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A mother raising a child with mental illness is often caught in the vortex of needing public services, battling with negative public perceptions of the mentally ill, and trying to raise a family. The barriers to receiving help are steep and the blame for these children's illness is placed solely on their parents; most often, the parent most responsible for care and most vulnerable to blame is the mother. The intersection of race, class, and gender, coupled with the need to access a provider-driven system, robs such mothers of power, voice, and identity. This lack of voice, and the accompanying feelings of powerlessness, is not unique to the parents in this study.

The quality of children's mental health services remains a serious concern for families, providers, and policy makers (Waxman, 2004). By the 1990s, the preponderance of negative outcomes for children with mental health challenges (Wagner, 1995), and the co-occurring strains on their caregivers (EvaluBrief, 2006) warranted substantial federal funding in the form of federal grants to create Systems of Care within states to improve outcomes for children experiences mental, emotional and behavioral health challenges. A core principle of the early SOC grants was the empowerment of parents through family-run organizations.

The purpose of this study was to understand the lived experience of parents who staffed family-run organizations funded under SOC between 1994 and 2011 in a single state. I used a qualitative, interpretive, phenomenological research method for this study. This method provided the lens and structure for data collection, analysis, and

interpretation through which I attempted to understand the phenomenon of parents who staffed family-run organizations under SOC. All of the participants are parents who staffed a family-run organization and who were raising a child with mental health challenges.

The two theoretical constructs that undergird this study are empowerment theory and feminist theory, with an emphasis on the role of identity (Groleau & Zelkowitz, 2009); specifically, a) identifying oneself as empowered (Zimmerman & Perkins, 1994); b) using voice, defined as the ability to identify your location in the social strata and to speak from your position about your position (Collin, 1989); and c) agency, which refers to taking measures to change the current situation through self-directed actions (Ahearn, 2001; Kabeer, 1999; Villaverde, 2008).

This study shows the transformative power of the family-run organization model through a gendered lens that examines the roles of class, race, and gender. In just a few years, mothers with limited resources went from feeling powerless to feeling powerful, from feeling devalued to valuable. These feelings were accompanied by actions that speak to the behavioral component of empowerment, in a manner that is reflective of the unique ways that women behave in roles of leadership and power. In this research project, I have privileged parents' voices as a way to make meaning of their experiences as women and mothers; add to their positive concepts of self-identity; and refute the master narratives—all while presenting lessons that can inform other families as well as providers and policy makers.

THE PHENOMENON OF TRANSFORMATION FROM HELP SEEKING TO HELP  
GIVING: THE ROLE OF FAMILY-RUN ORGANIZATIONS

by

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## **CHAPTER I**

### **INTRODUCTION**

Within each person lies a bone-deep longing for freedom, self-respect, hope and the chance to make an important contribution to one's family, community and the world. Without healthy outlets for this powerful, natural longing, the desire for freedom turns into lawlessness, and the need for self-respect is expressed in aggression and violence. No government program can help families become self-reliant, contributing members of their communities unless it is built on a recognition of the power of this bone-deep longing for freedom, self-respect, hope, and the chance to make an important contribution.

—C. Dean, Cornell University, 1996

This study explores the experiences of parents who staff family-run organizations under System of Care (SOC) demonstration grants awarded to a single state. Herein I couple a constructivist approach with interpretive phenomenological methodology to investigate the lived experiences of eight mothers, all of whom shared the phenomenon of staffing a family-run organization under SOC demonstration grants between 1994 and 2011. Each family-run organization focused on providing support to parents who were raising children with mental health challenges and on influencing the child mental health system overall. All of the parents I interviewed were also raising a child who had mental-health challenges. I used semi-structured interviews to capture the depth and significance of their experiences and analyzed them with the purpose of contributing to the scant amount of literature on this topic.

The following sections in this chapter include discussions of the historical and current concerns around children's mental health services and treatment options, the role

of the SOC as an alternative approach to serving children with mental health challenges and their families, and the role of the SOC in children's mental health services. This section concludes with a discussion of the significance of this study.

### **Children's Mental Health**

The United States has a deplorable history of providing care for people with mental illness, whether they are adults or children. Prior to the 1900s, the care of people with mental illness was appalling and dehumanizing (Mental Health America, 2013). Much of the poor care stemmed from a lack of knowledge about the causes of mental illness and from attributing the causes to such things as the devil, evil spirits, or weak moral fiber (Heflinger & Hinshaw, 2010; Hinshaw, 2005; Mental Health America, 2013). The treatment of children was often cruel and inhumane, including abandonment by their families, institutionalization, punishment, and even murder (Hinshaw, 2005).

Through the late 20th century, providing support to children with mental illness was primarily a concern of families and communities; local, state, and federal governments largely ignored children with mental illness (Mental Health America, 2013). Often when government did become involved, the state would remove children from their families and place them in institutions or residential treatment centers that could be located in a different state (U.S. Department of Health and Human Services, 1999). Most adults in the United States did not believe that children could have mental illness and therefore blamed parents for their children's behavior (Hinshaw, 2005). Because no meaningful activities were invested in the welfare of this population (Mental Health America, 2013) children and families were hidden from society.

In the early 1980s, Jane Knitzer's (1982) seminal book, *Unclaimed Children*, highlighted the extreme plight of families raising children with mental illness. This book encouraged advocates of children's mental health treatment to persuade federal, state, and local governments to address the deplorable care provided to this population. In the 1980s, the federal government responded by instituting the Child Mental Health program from which emerged the concept of the SOC.

### **Incidence and Prevalence of Children's Mental Health**

The incidence of children's mental health problems remains pervasive and difficult to diagnose because many parents do not seek treatment for their children due to cost, stigma (Hinshaw, 2005), or lack of knowledge about behaviors associated with children's mental illness (Mental Health America, 2013). Social, emotional, and behavioral problems are the most commonly recognized problems in children, especially when such issues are severe enough to negatively affect children's ability to function in home, school, or the community. Children's mental health concerns often interface with multiple child serving systems (Waxman, 2004).

Although it is common for young people to suffer from mental health concerns at some point in their lives, between 5% and 9% of young people ages 5 to 17, have mental health concerns that significantly impair their functioning (Costello, Compton, Keeler, & Angold, 1998; Substance Abuse and Mental Health Administration, 2011). Estimates by the federal Comprehensive Community Mental Health Services are even higher, reporting between 4.5 million and 6.3 million children with impaired functioning due to mental illness. In a longitudinal study conducted in North Carolina, researchers Costello,

Mustilo, Erkanali, Keeler, and Anglod (2003) reported that when the data were examined over a three-year period versus a three-month period, the prevalence of mental health problems among children in one age group soared from 13.3% to 36%.

The litany of negative outcomes associated with children with mental illness is well documented. Children with mental illness are twice as likely as their peers to drop out of school (Wagner, 1995), which leads to lower graduation rates for this population (Wagner, 1995; Waxman, 2004) as well as poorer work histories and poorer employment rates than children without such challenges (U.S. Department of Education, 2001). It is common for young people with mental illness to end up in the juvenile justice system (Waxman, 2004). Wagner (1995) reported that within three to five years after dropping out of school, the arrest rate for young people with mental health challenges is much higher than for young people who are developing typically. Between one-half and two-thirds of youth in juvenile justice settings have a mental health disorder, making “the prevalence of mental disorders much higher in juvenile justice settings than it is among youth in the U.S. general population” (Grisso, 2008, p. 150).

Compounding these serious consequences is the fragmented and inadequate service delivery system for children’s mental health. Because of this fragmentation, coupled with the stigmas of poverty and mental illness, up to 75% of children with mental health challenges do not receive appropriate services (Ringel & Strum, 2001). Poverty is an important factor in the ability to receive care. Given the disparity in insurance payments between care for physical health problems and mental health problems, in 2003 alone almost 13,000 children with mental health concerns were turned

over to state care by financially strained parents, through either the child welfare or the juvenile justice systems (Waxman, 2004). Care could be provided to children who were wards of the state, whereas private health insurance would not cover the cost of care for these same children. Waxman further reported that “14,603 youths were incarcerated unnecessarily in the first six months of 2003 because community mental health treatment was not available” (2004, p. 299). Among the treatments received by these youths, residential out-of-home placement was common. According to Waxman, “hundreds of children are locked in psychiatric care thousands of days after they have been cleared to leave, simply because less restive settings of care are unavailable” (2004, p. 299).

The statistics above indicate the need for treatment of children with mental health challenges. Another concern is there are not enough community care facilities; this lack necessitates sending children to expensive residential care settings (Waxman, 2004). The exorbitant cost of care in such facilities, coupled with the loopholes that permit private insurance companies to disallow provisions for mental health challenges, force many parents to do the unthinkable and give their children over to the care of the government in order to receive mental health treatment. In 2008, the Mental Health Parity and Addiction Equity Act became law (Mental Health America, 2013). Under this law, all group health insurance plans that cover more than 50% of their employees and provide coverage for mental illness and substance abuse disorders must provide those benefits in the same way as all other medical benefits they cover. Group health plans are not required to cover mental health or substance abuse benefits under this act, however (Department Health and Human Services, 2013).

Children with mental health challenges are likely to be involved with multiple service systems such as mental health services, substance abuse services, and juvenile justice services, as well as public school systems (Waxman, 2004). A 2006 study by the National Center for Mental Health and Juvenile Justice revealed that, nationwide, 70.4% of the children in the juvenile justice system had mental health disorders (Shufelt & Cocozza, 2006). These authors also reported that nearly 61% of youth with a mental health disorder also had a substance abuse disorder. These staggering numbers of school-age children are involved in multiple public systems including the mental health system and the juvenile justice system as well as school systems. All of these systems are stressed, and families caring for children with mental-health challenges comprise the most stressed system of all. Coordination of care among the service systems is virtually nonexistent because each operates with separate sets of criteria, policies, and practices.

Parenting a child with a mental health challenges comes with significant challenges. More than 16% of caregivers served by the SOC have reported being unemployed because of their child's mental health problems (Evaluable, 2006). Unsurprisingly, parents raising children with mental health challenges are more likely to be poor and to report higher levels of financial strain than reported for parents raising typically developing children (Evaluable, 2006). Caregivers' mental and physical health also suffers. Studies have reported increased feelings of sadness, worry, and guilt among caregivers (Heflinger & Brannan, 2006; Holden & Santiago, 2000). These feelings, along with financial strain, contribute to parental fatigue (Heflinger & Brannan, 2006; Holden & Santiago, 2000). A leading expert on stigma, Stephen Hinshaw (2005)



identified objective and subjective barriers that parents experience when caring for a child with mental illness. Subjective barriers include financial strain, the challenges of navigating systems for care, and basic/routine logistical concerns such as transportation and housing. Objective barriers, which are rated higher by parents, include emotional strain, mental anguish, and the societal shame and stigma associated with mental illness.

Stigma is a form of discrimination that ultimately results in oppression (Hinshaw, 2005; Link & Phelan, 1999) and is a significant barrier to care (U.S. Department of Health and Human Services, 1999). Stigma can create senses of shame, embarrassment, and hopelessness that prevent “people from seeking treatment and from taking part in civil society” (U.S. Department of Health and Human Services, 1999, p. 6). In addition, the negative stereotypes that result in stigma directly affect the public’s willingness to pay for mental health services (Brauner & Stephens, 2006; Hinshaw, 2005; U.S. Department of Health and Human Services, 1999).

Nor are mental health professionals immune from engaging in stigmatizing behaviors (Hinshaw, 2005). Although people in the mental health field are the designated professional helpers for young people with mental illness, research shows that they, too, practice stigmatizing behaviors toward the population they are supposed to be serving. Hinshaw (2005) and Heflinger and Hinshaw (2010) highlighted the forms stigmatizing behaviors take and the impact of those behaviors on young people and their families. These authors contended that the stigmatizing views held by professionals might not be conscious; nonetheless, they exist and are conveyed through comments and actions. Negative attitudes on the part of professionals toward people with mental health

challenges can be harmful and damaging because they can contribute to feelings of worthlessness and low self-esteem in patients (Hinshaw, 2005).

### **System of Care**

With a greater understanding of the need for action, in 1992 Congress formed the Comprehensive Community Mental Health Services for Children and Their Families Program under the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (SAMHSA) (Department Health and Human Services Substance Abuse, Mental Health Services Administration, 2013). System of Care was developed to address the complex and seemingly intractable problems in the children's mental health system. It has been funded since 1984 and there are currently there are 57 active SOC communities in the U. S. through Child Mental Health. As designed, the SOC is both a philosophy and an approach, sponsored by the Child Mental Health Services Branch of the federal government and administered through state agencies. By formal definition, it is "a comprehensive spectrum of mental health and other services and supports organized into a coordinated network to meet the complex and changing needs of children and their families" (Stroul & Friedman, 1986, p. 3). Stroul and Blau (2009) further described the SOC as a dynamic system that is adaptable to local communities. This adaptability results in a fluid definition applicable to diverse communities and service systems such as children's mental health, juvenile justice, and child welfare (Stroul and Blau, 2009).

The stated SOC values, which add further depth to its mission, mandate care that is child centered, family focused, and culturally competent. The guiding principles also

specify that services should be community based and should be provided in the least restrictive appropriate settings, coordinated both at the system and service delivery levels; involve families and youth as full partners and emphasize early identification and intervention (Stroul & Friedman, 1986). These authors also contended that the values and goals that undergird the philosophy of SOC are critical and take precedence over strict adherence to its formal definition. Federal dollars are provided as seed money to states that have applied for funds to adopt the SOC's principles and philosophy as a way to reform their child mental health systems. After the time-limited grants end, the funding localities are expected to have incorporated the philosophy of the SOC and its attendant principles, and to have identified mechanisms to continue funding these programs based on the SOC philosophy.

Through these time-limited SOC demonstration grants, states are provided with federal funds to both improve publicly funded services for children's mental health and, at the same time, provide a mechanism for parents of these same children to impact services through their participation in the service delivery and policy processes. One of these mechanisms is family-run organizations, which were developed as mediating structures between the families who lacked power to obtain services and the powerful professionals who provided needed services. Family-run organizations were designed to help families reclaim their sense of power and to provide a mechanism for changing the paradigm of service delivery.

Throughout this dissertation, the use of the word "parent," as defined by SOC is as follows:

. . . an individual who is a primary caregiver for a child, youth, or adolescent with a serious emotional disturbance (an emotional, behavioral, or mental disorder). The primary caregiver may be provided with a significant level of support by extended family members. Families who have children, youth, and adolescents with a serious emotional disturbance are organized in a wide variety of configurations, regardless of social or economic status. Families can include biological parents and their partners, adoptive parents and their partners, foster parents and their partners, grandparents and their partners, siblings and their partners, kinship caregivers, friends, and others as defined by the family. (Department Of Health And Human Services Substance Abuse and Mental Health Services Administration Center for Mental Health Services, 2003)

In the human service delivery system, the term “parent” most frequently applies to a mother. All of the parents who participated in this study are raising children with mental health challenges referred to as serious emotional disturbances, and all of them, with the exception of one, have incomes low enough to allow their child to qualify for public mental health services. All of them are women.

### **Classification of Serious Emotional Disorders**

The term “serious emotional disorders” (SED) is not a diagnosis, but rather an umbrella term used to classify a group of children who need services due their behavioral or emotional challenges (Brauner & Stephens, 2006). Some common diagnoses that fall into the general category of SED are ADHD, anxiety disorder, bipolar disorder, conduct disorder, eating disorders and, post-traumatic stress disorder (PTSD) (National Dissemination Center for Children with Disabilities, 2010). In the 2003 grant application instructions for SOC sites, the federal Children’s Mental Health branch stated that for a child to qualify for services under an SOC-grant funded program, he/she must be under 21 years old (the age range varies from year to year of grant awards). For the grant years

covered by this dissertation, the age range was 6 to 21 years. This grant application further stated that:

To participate in the SOC, all children must have a diagnosable emotional, behavioral, or mental health disorder. These disorders must impair their ability to function in the family, school, or community, or in a combination of these settings. In addition, this decrease in the level of functioning requires that the child is being served by two or more agencies. SED is of longer than one-year duration and is expected to last more than one year. (Department Of Health And Human Services Substance Abuse and Mental Health Services Administration Center for Mental Health Services, 2003)

The federal SOC request for applications in 2003 defined a family-run organization as:

. . . a private, nonprofit entity that meets the following criteria: Its explicit purpose is to serve families who have a child, youth, or adolescent with a serious emotional disorder (children, youth, and adolescents who have an emotional, behavioral, or mental disorder). It is governed by a board of directors comprised of a majority (at least 51 percent) of individuals who are family members. It gives preference to family members in hiring practices and it is incorporated as a private, nonprofit entity (i.e., 501 (c)(3)). (Department Of Health And Human Services Substance Abuse and Mental Health Services Administration Center for Mental Health Services, 2003)

As mentioned, SOC began as a philosophical approach to serving families raising children with mental health challenges that are severe enough to disrupt functioning at home, in school, or in the community (Stroul & Friedman, 1986). The emerging philosophy behind this approach called for full partnerships between service providers and parents seeking to access services for their child's mental health challenges. To provide assistance to family-run organizations and to enhance the partnerships with providers, the federal government provides funds for a national family-run organization. The Federation of Families for Children's Mental Health (hereafter, the federation). The

federation has codified the definition of parent participation and expanded it to include families as full partners in service delivery. This definition was further expanded and conceptualized as “family-driven care,” complete with its own set of guiding principles.

Family-driven means families have a primary decision making role in the care of their own children as well as in the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes: 1) choosing supports, services, and providers; 2) setting goals; 3) designing and implementing programs; 4) monitoring outcomes; 5) partnering in funding decisions; and 6) determining the effectiveness of all efforts to promote the mental health and well-being of children and youth. (Federation of Families for Children’s Mental Health, n.d., p. 1)

These six principles delineate the role of parents in service systems reform and the relationship between providers of services and the families receiving services. The federation, in partnership with the Substance Abuse, Mental Health Service Administration (SAMHSA), the federal administering body, developed and embedded family-driven principles into the policy language of SOC. These principles clarify the role of parents and family-run organization in systems transformation, peer support, services, and treatments for their children with SED. Additionally, these principles specify that funding should be provided to support the inclusion of family voices in SOC communities (Federation of Families for Children’s Mental Health, n.d., item number 7).

### **Role of Empowerment in SOC**

Empowerment leads to the acquisition of resources, power, and control it is the ability of individuals and groups to influence life events that are important to them (Kuokkanen & Leino-Kilpi, 2000; Rappaport, 1981, 1987). Empowerment is a both a means for achieving social justice and a transition from a state of powerlessness to a state

of improved control over one's life, fate, and environment (Conger & Kanungo, 1988; Gutierrez, 1990; Perkins & Zimmerman, 1995; Rappaport, 1981; Rees, 1998; Rose, 2000; Sadan, 1997). Scholars further describe empowerment as both a vehicle for citizen participation and an essential need born of our humanity (Kuokkanen & Leino-Kilpi, 2000; Rose, 2000; Sadan, 1997; Zimmerman, 1990) and is a necessary component for developing our full human potential (Kuokkanen & Leino-Kilpi, 2000; Rees, 1998; Sadan, 1997). Empowerment challenges hegemonic structure by creating pathways for personal growth and development that allow for participation in the decisions that impact one's life (Gutierrez, 1990; Kuokkanen & Leino-Kilpi, 2000; Sadan, 1997).

SOC, with its empowerment philosophy (Knitzer, 2005), is now a widely accepted approach to serving children with mental-health illnesses as well as their families. Both the 1999 U.S. Department of Health and Human Services Report to the Surgeon General and President George W. Bush's New Freedom Commission on Mental Health (2003) referenced the efficacy of SOC as a service delivery approach. Federal expenditures for SOC are notable; Rosenblatt (2009) reported that monies for implementation alone exceeded more than \$1 billion in 2009.

The recognition of SOC as a viable service model, coupled with its significant amount of federal financial support, makes SOC a national model of significance. It is important to note, however, that although the SOC philosophy continues to be promulgated and funded, the emphasis on partnerships with parents has steadily decreased. For example, the 2013 SOC proposal announcement posted by SAMHSA includes the statement, "Systems of Care build meaningful partnerships with families

...” (SAMHSA website, 2013). The shift in chosen language from “developing independent family-run organizations” to “meaningful partnerships” is significant because it speaks to the shifting roles for parents within the SOC. Curiously, the ongoing national evaluation of SOC has failed to capture the experiences of parents who staffed these organizations. Nevertheless, because of this failure it is not surprising that we know little about the roles played by these organizations in the long-term impact on such parents and even less about what happens to the organizations and the parents who staffed them after the federal funding ends.

Between 1999 and 2011, this U.S. state for which I am basing my study, received several federal SOC demonstration grants whose provisions required family-run organizations. In addition to county-funded SOC programs, this state has a statewide family network that is funded by SAMHSA. The latter organization is also a family-run organization; parents who are raising children with mental health challenges comprise more than 51% of its board of directors. A separate category of federal funding exists for statewide family network grants.

The SOC approach has provided much-needed services and supports to families raising children with SED. The research component of the federally funded SOC sites has created a new understanding of children’s mental health and research on promising and evidence-based practices. The goal of keeping children in the least- restrictive environments lowers the costs of care and frequently allows children to remain with their families. The use of federal funds to support family voice and family organizations to reduce stigma has elevated the discourse on these important topics. Family voice refers



to the ability of parents to speak up and voice their opinions, concerns, and choices regarding the services they receive. Families involved with SOC have increased their skills and knowledge of the child mental health system (Osher & Osher, 2002), started organizations, and provided valuable support to other families.

Although federal funds through the SOC grant sites support family voice and has supported family-run organizations, the basic premise for this concept must be unpacked. Caregivers within SOC are more likely to be poor, single, female parents who also cope with high job instability and tremendous worry and stress about their children and families. Because more children with mental illness are remaining in the home instead of going into residential settings, parents have the additional responsibility of caring for them, often without respite and support (Huang et al., 2005).

### **Rationale for this Study**

This qualitative study uses a constructivist approach paired with interpretive phenomenological methodology to investigate the lived experiences of eight participants to understand their experiences of staffing family-run organizations dedicated to improving children's mental health. Using semi-structured interviews, the depth and significance of their experiences were captured and analyzed with the purpose of increasing the available literature on this topic. The goal is for this study to add to the body of knowledge on family-run organizations for children's mental health.

That family-run organizations as well as statewide family networks were funded under the SOC specifically for children's mental health speaks to the commitment of the federal government to family empowerment. The last funding year for a SOC grant for

the development of a family-run organization was 2003. The 2005 SAMHSA grant notifications included language on family-driven care and family involvement, but lacked the specification of an independent family-run organization (Center for Children's Mental Health, 2005). Government support for SOC has continued, but without language in grant applications or funding to support the development of independent family-run organizations.

Many stories have been told about these parents and their children. Practitioners who have participated in writing SOC grant proposals for federal funding, including myself, have reported stories of the lives of parents raising children with mental illness from a statistical perspective. These sagas were often tales of woe that relied only on the dire statistics that I share in Chapter II. Negative stereotypes about low-income families and children with mental health disorders prevailed among these accounts. Nonetheless, these families needed federally funded SOC programs or dreadful outcomes awaited them. The statistical portrayals of their children were equally bleak. Statistics on school failure and dropout rates, juvenile delinquency, and incarceration rates implied dismal futures for these children. As a corollary to the oft-touted, real negative outcomes for parents and their children with mental illness, there has not been much acknowledgement of the strength, fortitude, and resiliency of these parents and their children (Knitzer, 2005).

There are, however, some exceptions. Hinshaw (2005) wrote that "for at least a subset of families [where there is a child with mental illness], this experience [of raising a child with mental illness] has fostered sensitivity, courage and a more positive outlook on

life” (p. 722). Jane Knitzer, who first wrote about the current lack of services for children with mental illness, also chronicled the commitment she witnessed among the parents of children with mental illness, as well as their resiliency and tenacity (Knitzer, 2005). My personal relationships with families raising children who have mental illness have left me humbled. My desire to share the stories and voices of these families strongly influenced my decision to undertake this doctoral project.

The ongoing national evaluations commissioned and paid for by the federal funding agency told yet another story regarding these families. The evaluation objectives were focused on child behavioral outcomes in home, school, and the community, and the data about these outcomes were portrayed as an overall mental health rating on validated scales. Although the general statistics reported were valid, these measures alone failed to represent the full experiences of individual families. These numbers tell only one part of the stories the families would have told about themselves, their children, and their lives—and about the joys and challenges of their efforts to support other families and to reform the mental health system through family-run organizations. I believe that listening carefully to the parents who experienced the phenomenon of staffing family-run organizations and interpreting these experiences are an important, untapped component of the SOC program model.

While SOC federal funding was available for constructing family-run organizations, parents were involved all aspects of SOC. They also had a peer-support network and a constituency of other parents in the organizations themselves. These parents provided valuable services such as peer support to other parents, participation as

members of policymaking bodies, and provision of training to parents and practitioners alike. Parents were paid a stipend, provided for in grant funding, for their participation on committees and for attending meetings. However, once the influx of federal dollars ended, family-run organizations in this U.S. state showed a sharp decline in providing state or local funds to support the continuing role of parents in family-run organizations. As a result, related expenses such as travel forced many parents to stop their participation. Even worse, the hard-learned lessons and valuable experiences of the parents who had participated were not captured as future teaching and learning tools for other parents involved in the child mental health system.

These lessons are not yet lost, however. I believe that we must hear parents tell their own stories, from their own lived experiences, in their own words. To date, parents' stories about their involvement in family-run organizations in the SOC demonstration sites remain untold; the national evaluation of the SOC demonstration sites did not capture their voices, nor could I find any other studies that relied on parents telling their stories, their way, in their own voices. Through analysis of individual interviews with parents who staffed family-run organizations under the identified federally funded SOC grant sites, this study provides a mechanism for parents to make sense of their lived experiences and the impact of those experiences on their lives. It can also provide valuable information regarding the efficacy of family-run organizations.

### **Personal Interest in Family-Run Organizations**

For more than 25 years, my professional work has centered on a commitment to help service systems develop policies and practices that are respectful, effective, and

accountable to the families they serve. After a short time, my professional work shifted into working with health and human service policies and practices to make them more inclusive and democratic. I soon learned that creating policies was not enough.

Although policies could and did contain language that was clear and well intentioned, they often lacked funding, mandates, or the will of the people to carry them out. Shifting again, I began developing and implementing training to encourage attitudes and beliefs that would enable the policies to be carried out as intended. I soon learned, however, that training on its own was not enough to create change. Shifting once again, I began providing technical assistance and support to recipients of the policies who were organizing themselves into groups to provide what the professionals were not.

Although I already knew that change happens, albeit slowly, I began to recognize an undercurrent and forces were at play that I did not grasp. Systems were not changing; professionals and families were not collaborating to make changes; and those languishing without services continued to languish. Guided by the principles of empowerment and partnership, my goal was to facilitate change in individuals, families, and communities.

In 1997, I received my first contract to assist in implementing SOC and its principles. At that time, I was an independent contractor. Since my initiation into SOC in 1997, I have acted as an advocate for and a resource to parents staffing family-run organizations. I have provided training and technical assistance to providers to assist them in improving their services, forming partnership with parents and implementing the SOC principles in their respective disciplines. My commitment to family-driven care has deepened through my direct interaction and relationships with the parents who staffed the

family-run organizations and the program administrators who believed deeply in the philosophy undergirding SOC. I supported the mothers as they learned to navigate the world of non-profit development. I watched as they developed their skills, collaborated with practitioners as equal partners, and then assumed practitioner roles. However, once the federal funding ended, so did the parents' ability to participate at the same level and in the same manner. I observed the demise of the family-run organizations after the federal funding ended.

Although the funding may have ended the parents continued to be parents; their children continued to have mental health challenges; and the service systems continued to provide limited services. The stories of these parents and children continue to evolve even though federal funding for the family-run organization no longer exists with the SOC funding. The state included in this study did not continue to fund the family-run organizations after the federal grant money ended. The story of the publicly funded human service systems, the rollout of the SOC, and the families whose lives became intertwined with these systems are presented in the following chapters of this dissertation.

This introductory chapter has laid out the purpose of the study, the study methodology, and a brief overview of the issues involved in both the disempowerment and empowerment of parents raising children with mental health challenges. In addition, this chapter provided a backdrop to the incidence and prevalence of children's mental health and the challenges faced when accessing services. I also provided a background on the development and implementation of SOC.

In Chapter II of this dissertation, I trace the evolution of publicly funded human services with an emphasis on child mental health services and the stigma associated with mental illness. Chapter II also includes a discussion of the role of power within human services and the implications of both race and gender. From there, I go into a deeper discussion of the etiology of publicly funded human services and their evolution into empowerment-based services. Chapter II culminates with a review of theoretical frameworks of feminist theory and empowerment theory, the two major theoretical traditions that inform this study.

In Chapter III, I present the study methodology, provide the framework for the use of interpretative phenomenology, and trace this methodological framework back to the philosophical work of Martin Heidegger. I also discuss the role of the researcher, the mechanisms I used to ensure the trustworthiness of the study, and the mechanisms for the study implementation. Chapter III also contains a review of issues of power and ethics related to qualitative studies in general and to this study in particular. Chapter IV presents an analysis of the data and details about the identified themes, supported by direct quotes from participant interviews. Chapter V includes details the research findings through the lens of the theoretical frameworks presented in Chapter III. Finally, Chapter VI ends this dissertation with a comprehensive discussion of the data and areas for future study.

### **Conclusion**

This study is about the experiences of parents who staffed family-run organizations under SOC grants in one state. My use of interpretive phenomenology

allowed me to hear from the parents, in their own words—something that has rarely happened in previous research on this topic. My goal is for this study to help inform policy makers and human service practitioners of the role family-run organizations have played in the lives of parents.

Parents of children with mental illness remain an underrepresented group in children's mental health services. In an age of evidence-based practices (Scott & Proescholdbell, 2009), the dearth of data on family-run organizations contributes to their decline after the funding ends. Without data to support the viability of family-run organizations as a stable, effective source of intervention, they become unacceptable practice models.



## **CHAPTER II**

### **LITERATURE REVIEW**

#### **Introduction**

I begin my overview of the literature related to the topic of this dissertation by examining what we know about the impact of family-run organizations under SOC. From there, I briefly examine the traditional role of parents in the publicly funded systems designed to service their children, with a specific focus on the child mental health system. In the next section, I consider populations of people who qualify for publicly funded services and discuss the roles of poverty, race, gender, and class. In subsequent sections, I discuss the role of narratives, individual, community, and dominant cultural narratives—not as a method of research, but as a way of understanding the impact of the intersection of poverty, race, gender, and class upon the people who are receiving services.

I also highlight the parent movement in human services as an example of the power shift from the current hierarchical human service system to a system based upon SOC principles. I initially describe the parent movement related to children with developmental disabilities, because it was the first parent movement in this area and, to date, remains the most sustained one. From there, I discuss the parent movement that mostly is mothers resulting in family-run organizations. This chapter ends with overviews

of feminist theory and empowerment theory as the theoretical traditions that inform this study.

### **Power, Patriarchy, and Services for Families**

A cursory look at the history of public sector human services reveal what seems to be a system focused primarily on saving children. However, below this veneer a much more complex agenda strives to maintain White hegemony and a patriarchal power structure that both regulates labor markets and achieves social control (Handler & Hasenfeld, 2007; Katz, 1996; Neubeck & Cazenave, 2001). As described in Chapter I, the term “parent” is a broad generic term that, in reality, most often refers to a mother. If a parent (a mother) is accessing public mental health service systems, she has an income low enough to qualify for public services. Blaming a mother for a child’s perceived problems or failures in any arena is certainly not a new concept (Ladd-Taylor, 1998). However, this blame takes on a special significance when the mother has few financial resources and is further marginalized due to her gender and/or race. I delineate the significance of this marginalization in the following sections.

### **Poverty**

Insufficient financial resources to care for your family is a prerequisite for receiving publicly funded human services, including child mental health services. Paradoxically, prior to receiving any services, one must already be struggling financially. The federal government sets a poverty threshold as a measure of eligibility for services. These income levels are relatively low, which means that people must be struggling sufficiently with enough finances to care for their families before they can access welfare

services that provide valuable and even essential resources such as food, housing, health care, education, and training.

The current political rhetoric around government spending, particularly on programs for the poor, has caused many people to blame those in poverty for “draining” the government coffers (i.e., the taxpayer-funded system through which the government provides services and supports to families with children). These supports include health and mental health services, food and housing subsidies, and cash payments through the welfare system. Pejorative messages about the people who use these services have added to already-bitter disputes among various political parties. This debate is not recent, but the vitriol associated with the current debate is quite significant.

In 2008, the incomes of 13.2% of the U.S. population, 39.1 million people, fell under the poverty thresholds (Bishaw & Renwich, 2009). Women comprised 59% of those in poverty (Weis, 2009). Based on U.S. Census data, Cawthorn (2008) reported that in 2007, more females than males were poor (13.8% and 11.1%, respectively). Of all women who were poor in 2007, 80% were single women with or without dependent children and 20% were married women with or without dependent children. In 2007, the largest single category of women in poverty was unmarried women with dependent children (Cawthorn, 2008).

Cawthorn (2008) further reported that across racial groups, women fare less well than men do. Women of color are particularly worse off. Of African American<sup>1</sup> women

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<sup>1</sup> In this dissertation, the terms “Black” and “African American,” and “Latino” and “Hispanic,” may seem to be used interchangeably. This is because there is no consistency in published documents. The terms used herein correspond to the terms I found in the original source materials.

and men, the incomes of 26.5% and 23% respectively fell under the poverty guidelines.

Among Hispanic women, 23.6% are poor compared to 19.6% of Hispanic men.

Although the percentage of White women in poverty at 11.6% exceeds that of White males at 9.7%, these comparative rates are much lower than those for people of color.

People of color are also overrepresented in comparisons of children in poverty by race. Although the poverty rates remained flat between 2006 and 2007 for Whites (8.2%), Blacks (24.5%), and Asians (10.2%), the number of Hispanics in poverty increased slightly (DeNavas-Walt, Proctor, & Smith, 2008). The statistic for those in deep poverty defined as income of less than 50% of the poverty threshold as defined by the federal government reveals similar results. Of these people, in 2007, 4.2% were White, 11.2% were Black, and 8.2% were Hispanic (DeNavas-Walt et al., 2008). The numbers for children living in poverty are staggering. According to the Children's Defense Fund (2008), more than 13 million children lived in poverty in 2007. For children represented in the poverty statistics, one in three is Black, one in four is Latino, and one in ten is White (Children's Defense Fund, 2008). While poverty remains a serious problem for many Americans, these problems are magnified for children, women, and people of color.

## **Gender**

Examining the public welfare system provides the most complete perspective on the role of parents. Public welfare policy is intimately connected to women. Women have been the focus of welfare policy and the recipients of welfare since the earliest public social welfare programs of 1900s. Daly and Rake (2003) along with Johnson,

Duerst-Lahti, and Norton (2007), have contended that social and moral values related to women and their roles are inherent in the policies and procedures that govern public welfare.

In the early 1900s, when social welfare policies were created in the U.S. specifically to aid poor women, the paradigms of traditional gender roles were obvious. The purpose of the Mothers Pension program, the precursor to today's welfare system, was to keep children out of costly institutions and have them remain at home where they could be properly, and less expensively, nurtured by their mothers (Katz, 1996; Neubeck & Cazenave, 2001). Aid to Dependent Children (ADC) replaced the Mothers Pension program in 1935 as part of President Roosevelt's New Deal (Abramovitz, 1996; Katz, 1996). The ADC policy continued many of the same gendered policies as its predecessors. However, under ADC an increased number of single women raising children received benefits because eligibility criteria and program standards had been unified across states (Neubeck & Cazenave, 2001). As a federal program, ADC it set forth a national paradigm of the role of government in response to poor women with children. According to Abramovitz (1996), "ADC substituted itself for the male breadwinner, judged female-headed households harshly, and subjected them to strict control" (p. 313).

ADC reinforced the notion that women belong in the home, raising children; therefore, it continued the "suitable home policies" that had been developed from the Mothers Pension program provisions (Abramovitz, 1996). These policies required women to keep homes that were conducive to raising children. In other words, the

mother's private behavior was a factor in whether the state provided support to her for raising her children (Abramovitz, 1996; Katz, 1996; Neubeck & Cazenave, 2001). The suitable homes policy also opened the door for government workers to inspect the homes of women who were receiving aid, a practice that further reinforced the patriarchal paradigm of forceful government intervention.

### **Race**

Starting in the mid-1960s, particularly after Lyndon Johnson's War on Poverty Initiatives, the idea that poverty resulted from the cultural defects of Black Americans and other people of color was solidified as cultural truth. Promulgation of this supposed truth by the media (Gilens, 1999) and other social institutions portrayed people on welfare as Black, promiscuous, and lazy (Abramovitz, 1996; Broughton, 2003; Dyck & Hussey, 2008; Handler & Hassenfeld, 2007); and as perpetrators of wide-scale welfare fraud (Kohler-Hausmann, 2007). The perceived association between Black welfare recipients and welfare fraud even prompted one city manager to order all welfare recipients to pick up their checks at the local police department (Kohler-Hausmann, 2007)! One of the most common affronts to Black women on welfare is the term "welfare queen," which has "symbolically transmitted multiple messages with derogatory, racial, gender, and class subtexts" (Kohler-Hausmann, 2007, p. 335). These negative portrayals of Black women on welfare, fueled by the assertion of their underlying pathologies, became the norm (Dyck & Hussey, 2008; Handler & Hasenfeld, 2007). These myths became part of the cultural fabric of the U.S. and, for many people, solidified as inalienable truths.

Often, this negative rhetoric supported the enactment of racially motivated policies that restricted access to services and authorized sanctions that have been more punitive for Black women. For example, Black women were denied participation in the early Mothers Pension program (Katz, 1996). Even ADC, the federal program that replaced the Mothers Pension program, denied access to Black women through many features that were included in individual-state discriminatory processes. In fact, as with all previous programs, ADC was not available to any family in which an adult male was present, thus denying services to married couples (Daniel, Shepherd, & Towey, 2007).

Black women today continue to bear the full weight of gendered, racist, and classist welfare policies. A growing body of literature presents the constructs of gender, race, and class as intersecting forms of multiple inequalities grounded in domination and oppression (Acker, 2000; Crenshaw, 1993; Ivy, 2007). Even the terms “gender,” “race,” and “class” are socially constructed and denote locations in the social hierarchy (Blankenship, 1998; Grills & Prus, 2008). These positionalities in the hierarchy “possess rank and have value” (Robinson, 1999, p. 73). The U.S. human service system embodies this intersectionality as it serves low-incomes, mothers, particularly mothers who are women of color and those that are raising their children alone. Disentangling the reasons why women are on welfare as they relate to gender, class, and race quickly becomes laden with conundrums: Are women on welfare because they are women with children? And, as such, are they subject to the inequities of lower pay, childcare responsibilities, and divorce laws that favor men? Alternatively, are these women poor because they are Black and carry the residual effects of slavery in a society still primarily governed by

White men? The answers to these questions are debatable. What defies debate is that many women remain in a lower socioeconomic class because (a) they are women; and (b) welfare benefits train them for low-paying jobs (Mink, 1999).

Although the meanings of the terms “race,” “class,” and “gender” are fluid across time and location (Ivy, 2007), under U.S. welfare policy their meaning and confluence meet in the pejorative term “welfare queen.” This term simultaneously connotes blames upon an individual for her gender and race and for her particular condition of poverty. This and other unfairly negative stereotypes that are deeply ingrained in the American cultural fabric amplify the persistent cry to cut welfare benefits even as they negate the larger political and social factors that created the current welfare system. These factors defy challenges to the historically created power and classist structure.

Many researchers contend that women and African Americans are overrepresented in the poverty statistics because of the historically racist, gendered, and classist policies of the U.S. government (Abramovitz, 1996; Daly & Rake, 2003; Handler & Hasenfeld, 2007; Neubeck & Cazenave, 2001). Since the days of the Charity Houses that provided services to poor women with children in the late 1800s in the U.S., this overrepresentation has caused a distinction to be made between the “deserving poor” (i.e., widows) and the “undeserving poor” (i.e., all other women in poverty) (Abramovitz, 1996; Katz, 1996; Neubeck & Cazenave, 2001). For example, deserving mothers whose poverty was a result of widowhood have received public support, whereas divorced women have traditionally been ineligible for benefits in many states (Katz, 1996). To eradicate the assumed moral deficits of poor women, one function of welfare policy was



their cultural retraining as a means of inculcating dominant traditional values (Broughton, 2003) and thereby rooting out the pathological values that have been assumed to cause their poverty.

### **Tracing the Role of Parent Involvement in the Services for Their Children**

To trace the evolution of family-run organizations, I begin with a historical perspective of human service delivery in the U.S. People accessing public services for needs related to poverty, mental illness, or other debilitating life conditions may be vulnerable due to their gender, income, race, or disability (Tanner, 1998). Family social services are the means through which the U.S. government provides support to vulnerable families and children. Over the years, family social services has evolved from a piecemeal effort to a system of institutionalized services offered through large bureaucratic organizations (Katz, 1996). The provision of family services has grown from serving primarily poor single-parent families to include service provision for the elderly as well as people with disabilities and other life impediments. The types of services provided to poor families are numerous and include cash assistance, food stamps, maternal health services, and the Earned Income Tax Credit (Walt, Proctor, & Smith, 2007).

Historically, the three major welfare programs in the U.S. are the Mothers Pension programs, the precursor of welfare for female-headed households; Aid to Dependent Children (ADC), first enacted in 1935 under the New Deal and then changed to Aid to Families with Dependent Children (AFDC) ending in 1996; and the current welfare reform program, Temporary Assistance to Needy Families enacted in 1996.

Before the twentieth century, families with children navigated poverty with a little help from philanthropic individuals, charity organizations, poorhouses, and their communities (Katz, 1996). In the late 1800s, however, attention shifted from poor families to poor children. According to Katz (1996), “Throughout the country, by the 1890s children had captured the energy and attention of social reformers with an intensity never matched in any other period of American history” (p. 117). Without a doubt, life was brutal for children living in a family experiencing poverty. These children could be sold to people who needed labor, given up to institutions for their care, or put to work earning money for the family (Katz, 1996).

In the early 1900s, during the Progressive Era, the U.S. government formalized its role as a source of support to families in poverty with the primary purpose of saving the children (Katz, 1996). Out of concern for the country’s youngest citizens grew the family preservation movement that enacted child-labor laws and compulsory education laws that helped move children out of the labor force and back into the family, as children rather than sources of income (Katz, 1996). However, if children were to be at school and in the home, mothers with little income need supports that would allow them to keep their children at home. This concern for children birthed the first form of public cash assistance for poor families in the U.S., the Mothers Pensions (Abramovitz, 1996; Katz, 1996; Nuebeck & Cazenave, 2001). As its name implies, the Mothers Pension programs were for married women with children. Furthermore, these programs specifically targeted women who were deemed “deserving” of aid in that they were poor due to widowhood (Abramovitz, 1996; Katz, 1996). The 1935 Economic Security Act included

Aid to Dependent Children (ADC), which provided federal money to support states in their efforts to provide Mothers Pensions (Nuebeck & Cazenave, 2001).

ADC became Aid to Families with Dependent Children (AFDC) under President Lyndon Johnson's War on Poverty initiatives in the 1960s, as was part of a dramatic increase in government expenditures to alleviate poverty (Dobelstein, 1999). By the late 1960s, the federal government was providing many non-cash, means-tested programs such as Medicaid, food stamps, child nutrition and health programs, and cash subsidies to low-income families with children (Walt, Proctor, & Smith, 2007).

### **Relationships between Providers and Parents**

Given the historical origins of the human service system in the U.S., it is easy to understand the often-contentious relationships between service providers and people accessing needed services. The human service delivery system is a provider-driven system that operates from a top-down paradigm, with a bureaucratic and hierarchical structure (Katz, 1996; Nelson, Lord, & Ochocka, 2001; Osher & Osher, 2002). Service providers represent the top of the hierarchy because they hold the power, control, and resources (Dietz, 2000; Fondacaro & Weinberg, 2002). People who are accessing services represent the bottom of the hierarchical structure.

Most practitioners enter the human service system with a desire to be helpful. Unfortunately, many practitioners are removed from the day-to-day experiences of the people who need their services, and many providers have no personal experience with the issues being addressed. For example, many of the professionals who fund, administer, implement, and evaluate children's mental health services have never raised a child with

mental illness or other disability, nor they have ever experienced poverty. However, well- intentioned, the reality is that the decisions professions make on behalf of a family may be devoid of real-world experiences with the issues at hand and/or knowledge of the particular strengths of and challenges facing each family. Despite this real lack of knowledge and experience, professionals are granted the privilege of making decisions for others because of their status as helping professionals, their educational degrees, and their employment status. Professionals hold the power invested them by laws that grant such powers to them (Leiter, 2004).

When parents seek services for their children, they become objects of blame for their children's problems, and thus become the targets of interventions for their own perceived deficiencies as well (Turnbull, Turbiville, Turnbull, 2000). The decisions professionals make regarding services for the families they serve are influenced by a variety of factors including their professional training, their values and beliefs, the policies and practices of the organizations they work for, their professional guidelines, and the extent to which they are influenced by the dominant cultural narratives told about people who need services. Professionals exert control "through perceived higher competence, professional communication, and control of environmental resources" (Turnbull et al., 2000, p. 631).

Unfortunately, these decisions affect families in profound ways that can result in the loss of self-esteem and in self-devaluation. Parents, who possess valuable lived experience, become excluded from policy and funding decisions that impact them and their families. Tragically, for these reasons they are also excluded from the decisions

made for their own families and children (Osher & Osher, 2002). Viewed as an impediment to the professional interventions designed for children, parental voice has been largely ignored. With families removed from meaningful decision-making, a culture of professionals as experts has emerged (Osher & Osher, 2002). Gradually, families became passive recipients of services rather than active participants in their own aid. This enforced passivity has contributed to their sense of dependency and created adversarial relationships with providers (Natiello, 1990; Osher & Osher, 2002). Families and professionals alike have experienced frustration and anger as they have attempted to find or provide help and services. In turn, these emotions have often thwarted the helping process, to the detriment of all.

Upper- and middle-class families fought hard for their rights to be part of, and then to take the lead in the care of their children with physical disabilities (Leiter, 2004). Using methods borrowed from the civil rights movement, parents won significant legislative changes that specific their right to both lead and participate in service provision to their children (Grisso, 2008). From this fight, a new paradigm of parent/professional relationships was identified that mitigated the “power over” paradigm of professionals over families to a “power with” model of collaborative relationships between professionals and families (Turnbull et al., 2000). This parent-empowerment model, which has been promoted by parents and some professional partners, aims to reverse the paternalist, hierarchical services of the past and to legislate a new type of relationship in which shared power between professionals and parents is a central value.

### **Children's Mental Health Services**

Children's mental health services have followed a similar pattern of devaluing people who need the support of publicly funded human services. The mental health system, like almost all other human-service systems, emerged from a medical model. The philosophical approach behind this model was grounded in the tradition of experts with professional training, who diagnose problems and then prescribe solutions. These professionals supposedly use their expert judgment to prescribe treatment to resolve the presenting pathologies. This individualist approach to solving problems sought to isolate the causes of pathology and then remediate them. Unfortunately, parents were often identified as the primary cause of their child's mental health concerns (Tolan & Dodge, 2005; Turnbull, Turnbull, Erin, & Soodak, 2006); one popular remedy was to remove children from the source of the problem (the home) and place them in state institutions (U.S. Department of Health and Human Services, 1999).

### **Perceived Powerlessness in Human Services**

Power is pervasive and deeply entrenched in human service systems. Families, who are already disempowered by the nature of their socioeconomic status, disability, and cultural milieu, are further stripped of their power by the very systems designed to assist them. This devaluation results in a growing dependency on public services to solve problems for ill people and their families. Moreover, the lack of parental power to assist their children coupled with the internalization of devaluating messages, fuel feelings of hopelessness and negatively affects people's sense of identity. Sadan (1997) contended that "Disempowering social processes are responsible for creating a sense of

powerlessness among people who belong to groups that suffer from stigma and discrimination” (p. 144).

Powerlessness leads to a lack of self-worth, self-blame, and eventually indifference toward and alienation from the environment, aside from an inability to act for oneself and a growing dependency upon social services and specialists for the solutions to life’s problems (Sadan, 1997). Powerlessness results from a lack of power, either real or perceived. Power emerges from having control over resources and always exists within the context of social relationships (Foucault, 1982). Having power is about being able to modify the actions of others through access to, or control of, valued resources (Ewen, 1998; Foucault, 1982). Conversely, oppression stems from powerlessness that results in domination by others. Cudd (2006) defined oppression as “a harm through which groups of persons are systematically and unfairly or unjustly constrained, burdened, or reduced by any of several forces” (p. 23) and claimed it is “caused by social constraints” (p. 225). Oppressed groups are those at the bottom of the ranked social order of our society. Nonetheless, the oppression that results from a lack of power is not static. New knowledge and skills, which themselves are valuable resources, can increase an individual’s or a group’s actual or perceived power (Foucault, 1982). At the other end of the continuum from powerlessness is empowerment, which for the purposes of this dissertation represents a form of resistance to the inherent oppression of our hegemonic, patriarchal society.

Sadly, the people to whom these negative messages are applied can internalize them to the point that they influence their sense of identity, self-worth, and confidence

(Freire, 1972; Salzer, 2000). This internalization can create a destructive and self-perpetuating cycle that results in the further subjugation of those who are already marginalized due to their gender, race, and class. This contemptuous view of people in the lower ranks of the social order results in the devaluation and vilification of people who need support and succor. This vilification allows for those currently in power to continue the status quo and for the stories, they tell about the inaccurate identities of other groups to remain unchallenged.

### **Stories, Identities, and Dominant Cultural Narratives**

#### **Stories and Identity**

Narratives are stories, and telling stories is a uniquely human experience. Indeed, stories are a familiar and popular method of communication. Advertising, religion, and history all call upon the power of stories to deliver their messages. Stories are an integral component in all forms of human communication, accessible to everyone and used by everyone. In short, stories are universal means of communication (Groleau & Zelkowitz, 2009). They have a purpose and function greater than that of mere communication. Stories are the way we make sense of ourselves and our world (Groleau & Zelkowitz, 2009).

Through stories, we shape our identity (Somers & Gibson, 1994; Avest, Bakker, & Miederma, 2008). How we perceive ourselves, our identity, is constructed from multiple sources that include dominant cultural narratives that address power, women's roles, and agency (Alcoff, 2000). Our identity is also constructed through our standpoints, which often run counter to the master narratives (Collins, 1991). These



individual narratives, or self-defined standpoints, give meaning to who we are and the lives we lead (Collins, 1991; Groleau & Zelkowitz, 2009). Through stories, we begin to make sense of who we are in the context of the world in which we live. As Bloom (1998) wrote, “What is most important is how each narrator offers a means for the narrator to construct herself through the act of narrating stories” (p. 310).

Stories are the representation of events through the lens of the storyteller (Salzer, 2000). They have defining characteristics. They are comprised of events that are structured in a sequence that includes both time and themes (Dean, 1998; Mankowski & Rappaport, 2000). All stories are contextual and follow a similar sequence of beginning, middle, and end (Maines & Briddger, 1992; Salzer, 2000). Woven through the temporal context are a story line, related themes, and people (Salzer, 2000). This sequencing of information gives a story meaning that is unique to the storyteller (Dean, 1998; Mankowski & Rappaport, 2000). The meanings of stories, however, are fluid and can alter with new insights and experiences, and even interact with other stories, including dominant cultural narratives (Dean, 1998).

### **Dominant Cultural Narratives**

It is important to understand the form of stories described as dominant cultural narratives (Rappaport, 2000), which are powerful stories that influence both individual and community narratives. Rappaport (2000) described dominant cultural narratives as “the over-learned stories communicated through mass media or other large social and cultural institutions and social networks” (p. 4). These metanarratives or “master scripts” (Bloom, 1998) form the durable stereotypes that create stigma, as described in Chapter I

and lead to continued oppression for some groups of people. These stories are germane to the beliefs that form our cultural backdrop, which, in turn, shapes our identities and gives meaning to the identities of other groups and people (Mankowski & Rappaport, 2000; Rappaport, 2000). For example, the moniker “welfare queen” carries a back-story that depicts Black females who are poor as promiscuous cheats who are morally bankrupt (Katz, 1999). By denigrating others, in this case Black females, the White male power structure and the cultural hegemony is reinforced.

Another example of a dominant cultural narrative is the stigma that affects people with mental illness. Stigma “conveys a social identity that is devalued in a particular social context” (Crocker, Major, & Steele, 1998, p. 505). For example, people with mental illness are supposedly dangerous (Pescosolido, Gettes, Martin, Monahan, & McLeod, 2007). These stereotypes are representative of the stories told about a group of people that discredit them while, at the same time, elevating people who are not members of these groups. These cultural stories describe identities that are attributed to individuals, but they also create community identities that encompass everyone who belongs to a particular group.

Dominant cultural narratives can shape people’s perceptions of who is outside the mainstream while invading their subconscious minds with pejorative terms that describe people relegated to the margins. Dominant cultural narratives also create a set of identities for groups and people that do not necessarily reflect their reality. For example, television shows of the mid-twentieth-century such as *Leave it to Beaver* (1957–1963 and *Father Knows Best* (1954–1960) helped to create a dominant cultural narrative of the

mother who did her housework in a dress, high-heeled shoes, and pearls while waiting patiently for her wise and loving husband to come home from his office job. These television shows told a story of, and later created a nostalgia for, a period in American history that reflected the reality of only a very few, privileged people. Taken as reality, these stories were no truer than are the dominant cultural narratives that continue to depict poor people as morally bereft and people with mental illness as dangerous. However, these two types of narratives contain a unifying theme: they help maintain a White, elite power structure.

### **Community Narratives**

Outside of the dominant cultural narratives are the stories of people living different realities. These are the narratives of individuals, told from their unique standpoints. As Stanley and Bogusia (2008) wrote, “Narratives are always contextual, communal and relational” (p. 278). The parents who staffed family-run organizations did not do so in a vacuum. They were interacting with other parents who were also staffing family-run organizations, practitioners in the mental health field and other child-serving disciplines, and other families in need of services—all of whom, it can be assumed, were also steeped in the dominant cultural narrative. Community narratives can lead social actions and a “collective enterprise” (Azmitia, 1998, p, 242). Staffing family-run organizations was indeed a collective enterprise that, despite the current social milieu, led to new thinking and new action.

In other contexts, community narratives can refer to a form of research (Rappaport, 2000). I am not using community narrative as my research methodology in

this dissertation but as a way of understanding the stories that are common throughout the interviews. In the context of my doctoral project, communities are any groupings of people joined together for a common purpose such as a neighborhood, organization, or church (Mankowski & Rappaport, 2000; Rappaport, 1995). Community can also refer to people who are familiar with a common experience or phenomenon such as sexual identity, gender, chronic illness, or, as in the case of this study, who staffed a family-run organization under an SOC grant. Community narratives are the common stories people tell about their experience as members in a specific community (Maines & Bridger, 1992; Mankowski & Rappaport, 2000; Humphreys, 2000). Maines and Bridger (1992) contended that communities are dependent upon stories for their very existence.

Through communities, people can create and sustain new identities. Scholars in both empowerment theory and feminist theory agree that through narratives, marginalized populations can rewrite their stories from their perspectives and, in the process, expand their sense of identity (Collins, 1991; Rappaport, 1995). The individual narratives of people who experience common phenomena are combined and amplified to create a community narrative (Mankowski & Rappaport, 2000; Rappaport, 1995). These new stories may serve to counter the dominant cultural narratives.

Furthermore, these new stories help participants to understand their standpoints and the roles of the dominant cultural narrative formed by gendered policies. Rappaport (1995) further described this when he wrote, “The goals of empowerment are enhanced when people discover, or create and give voice to, a collective narrative that sustains their own personal life story in a positive way” (p. 796). Collins (1991) voiced the same

opinion when she wrote, “Self-defined, subjugated knowledge . . . empowers members of subordinated groups engaged in internal dialogues concerning their own standpoint” (p. 373). This empowerment happens best in supportive communities such as family-run organizations. Narratives and community narratives linked to empowerment have been used in studies of psychiatric consumers/survivors (Nelson et al., 2001), public housing residents (Salzer, 2000), Alcoholics Anonymous members (Humphreys, 2000), and religious-community members (Mankowski & Rappaport, 2000).

Last, stories were a common form of expression for the participants in this study. As part of their work in SOC, parents often “told their stories” for the benefit of service providers. The stories I heard parents tell referred most specifically to their unsuccessful experiences of seeking services for their children with mental health challenges, or they recounted the struggles these parents had experienced in raising a child with mental illness. The goals of these stories were to educate service providers so that they would support the SOC model and to elucidate the challenges families faced in accessing services. Many of the stories I heard were full of pathos, including the sorrow and heartbreak of parents as they fought the system for the care for their children.

Stories are also part of parents’ support systems (Dean, 1998; Humphreys, 2000) and functioned as part of the supportive services in family-run organizations. Parents used their stories to encourage and support other parents facing similar challenges. This support system often took the form of regularly scheduled parent-support groups. The goals of these support groups were to reduce isolation and to provide mutual support through the sharing of common challenges and struggles in raising a child with mental

illness. Parents' stories also had external purposes, such as educating funders and service providers. The stories were not used as a mechanism for parents to understand their own experiences and their roles in shaping human services, either of which would have enhanced their sense of empowerment. Nor were parents' stories examined as part of a reflexive consciousness-raising process that would help them understand that their plight was part of a system of domination and exclusion rather than their own doing.

As discussed earlier in this chapter, neither the perception of empowerment nor the feminist concepts of agency are fixed constructs. The ability to recognize personal power, claim it, and use it, are individual pursuits that most often occur in a community context. The collective story of parents can continue to enhance both their identification and their sense of empowerment, while validating their way of interpreting their experiences and informing policy makers.

### **Shifting to Empowerment-based Services**

The civil rights movement, the women's movement, and President Lyndon Johnson's War on Poverty initiatives of the 1960s fueled the shift in government to a philosophy of empowerment-based human service systems. Nonetheless, these reforms were often initiated by parents. Reforms in child-serving systems resulted in the premise that service recipients should have greater access to resources and decision-making (Hardina, 2003). There was a growing recognition that parents were an integral part of any effective service intervention and that their voices should be included in the process of designing services for and delivering services to their children. The result was a shift from the traditional model of service delivery toward a more empowerment-based

approach that engaged families as equal partners. In this new approach, the role of the practitioner also changed from the expert, a powerful bearer of resources, to more of a facilitator who assists families in acquiring needed skills and resources (Hardina, 2003). This shift represents the essence of empowerment-based services as well as a fundamental change in the power relationship within the helping systems of the U.S.

Head Start is a prime example of this policy shift. Created in the 1960s, Head Start is a federally funded early-childhood education program designed to reduce poverty through education and the empowerment of parents. According to Sissel (2000), “. . . this pioneering emphasis on parent involvement was focused on empowerment of the poor through parent involvement in decision-making in the program, and the development of economic self-sufficiency through job placement at Head Start Centers” (p. 54).

By the late 1990s, most of the child-serving systems in the U.S. had adopted an empowerment philosophy. Unfortunately, there was no consensus on approach to, definition, language, or principles of empowerment within human services. As disciplines began their own evolutions toward partnerships with families, they did so independently and with a focus on their own particular areas of service. This approach mirrored the current service delivery structure, with each system operating in a silo to serve a specific need or population. What followed were policies, principles, and language around empowerment-based practices specific to that discipline. The result has been a myriad of terms describing empowerment-based services: parent involvement, consumer involvement, family involvement, family-driven, family-professional partnerships, parent partners, family-centered practice, and shared leadership. These

terminologies refer to service-delivery approaches that share similar goals. The concern with this fragmented approach is that the movement for more effective responses and inclusive services has had no chance to coalesce; now parents, like service disciplines, compete for funding and recognition.

Another change in terminology has concerned how practitioners refer to recipients of services. As the service paradigm changed, so did the language used to describe the people who use the services. For example, people who accessed services were referred to as recipients, but the new terminology refers to those same people as consumers—a term that confers both rights and choices. This terminology change underscores the concept that the people receiving services are stakeholders in the process; as such, they know what they need and how best to obtain it. Parents of children receiving services, along with consumers of services, become partners with practitioners. Together, they can share power and gain control over resources.

Parents' acquisition of both resources and power ultimately results in increased knowledge and an increased ability to care for their families and improve their communities. The outcome of this new empowerment approach has been the provision of information, problem-solving skills, and political-action skills to participants (Hardina, 2003) that are meant to liberate them from the oppressive conditions and requirements of the helping systems. Under the early SOC grants, family-run organizations emerged as the primary mechanism for empowering parents. My sense is that this move was based on the very successful parent movement in the developmental disability field.



## **The Parent Movement**

The common perception prior to the 1940s in the U.S. was that a child with a physical disability was the result of weakness, parental defects passed on to the children, etc. (Groce, 1996; The ARC, n.d.). The dominance of this perception resulted in children being removed from the home and institutionalized, often for life. Parents were not included in the service decisions for their children. Furthermore, children with multiple mental and physical disabilities were not provided with an education—any education. They were not taught even the most basic skills, such as feeding and cleaning themselves, let alone slightly more advanced skills such as how to conduct routine tasks that were within their abilities.

The parent movement refers to roles of parents when they begin to rebel against services provided for their children and organize into collectives to create change. Parent movements have evolved in the U.S., as most movements do, in response to inequities and injustices, usually against a specific group of people. The most notable and effective parent movement is the fight for better treatment of children with physical and developmental disabilities. This is, in fact, an extremely successful parent movement. The United Cerebral Palsy Association, founded in 1949 and one of the earliest family-initiated organizations (Turnbull et al., 2006), was begun by mothers with children who had the condition. The parent movement for children with disabilities exemplifies grassroots movements. As early as the 1930s, American parents began seeking out other parents to connect with for support (The ADA Legacy Project, n.d.). This movement continued to grow as parents organized and became better able to raise funds for research

and, sometimes after years of advocating for legislative reform, pushed state governments and Congress to pass landmark legislation. The 1990 federal law named the Individuals with Disabilities Act (IDEA), which was the product of exactly this type of hard work, guaranteed children with disabilities the right to a free and appropriate public education (Wang, Mannan, Poston, Turnbull, & Summers, 2004). In addition, recent reauthorizations of this legislation, which was spearheaded by parent advocacy groups, detailed the roles of parents as accountability mechanisms for public schools (Wang et al., 2004). In 1975, the U.S. Department of Education began funding parent centers (PACER Center, n.d.) and in 1984, federal monies were increased to fund a national parent technical assistance center, PACER, and four regional parent technical-assistance centers (PACER Center, n.d.). Today there are 105 parent centers in the U.S. that are funded by the federal government (PACER, n.d.). A wide variety of private, nonprofit organizations related to specific disabilities are also in operation, such as United Cerebral Palsy, ARC, and March of Dimes, to name just a few. These are a few of the national organizations with hundreds of local chapters that render a multitude of services and supports to children with developmental and physical disabilities.

Before the 1960s, children with disabilities in the U.S. faced the same horrific treatment options and social stigma as children with mental illnesses. However, the parent movement for children's disabilities, by any standard, has been successful at getting funding for parent centers stable and legislated. As a result, the stigma around having a child with a disability or being a young person with a disability has been greatly reduced. While it is important to celebrate these ambitious and successful efforts by

parents to change both federal policy and dominant cultural narratives, it is equally important to note two things, the significance of which is elaborated further throughout this dissertation. One is that this is a true example of a grassroots movement (it emerged from an urgent need felt by parents and was started by parents); and the other is that the people who initially started this movement, and for many years were its backbone and leadership, were White, middle-class, married women (Groce, 1996). SOC family-run organizations are an example of what is termed the “parent movement.”

### **Family-Run Organizations under SOC**

Family involvement in children’s mental health in the U.S. is rooted in the fertile grounds of the peer-support, self-help, and consumer-rights movements of the 1970s. This early work gained momentum and recognition through federal legislation such as the 1984 Child and Adolescent Service System Program that provided support for the development of statewide family organizations (Briggs, 1996). This trend of increasing parents’ support of other parents was a major impetus for the increase in independent family-run networks, organizations, and groups. The distinguishing feature of family-run organizations was that the majority of the staff and volunteers were parents or caregivers raising children with mental health challenges.

Family-run organizations were analogous to parent centers in the disability movement, with one primary difference: they were mandated by federal SOC funding rather than emerging from a grassroots movement as the parent centers for children with non-mental health disabilities did. Lazear and Anderson (2008) described the activities of a SOC family-run organization as “providing peer support, ensuring access to services,

involving families in policy development, and altering the relationships between family members and providers” (p. 6). These activities are congruent to the activities listed by Maton and Salem (1995) for empowering settings, which include a strength-based belief system, opportunities to try new roles (including leadership roles), peer relationships that provide support, and a sense of community.

Family-run organizations offered an alternate setting to professionally driven, bureaucratic, hierarchical public mental health systems. The unique feature of family-run organizations under SOC was that parents of children with mental illness staffed them. Family-run organizations often served as mediating structures for the empowerment of families who previously had little voice and who were often blamed for their children’s mental illness (Rappaport, 1987). Family-run organizations helped parents move from being merely recipients of services to becoming providers of services. They embodied democratic participation and social justice by giving parents a collective voice and by providing parents the mechanisms with which to influence policy and program decisions that affected their families. In short, they represented an alternative to the traditional mental health service systems.

The concept of alternate settings emerged from the community psychology literature as a prevention strategy (Rappaport 1987; Saranson, 1972), which often arises in response to some unmet community need. Cherniss and Deegan (2000) contended that “creating an alternate setting is also a strategy for empowering people” (p. 362). Speer and Hughey (1995), in their work on community organizations, described the mechanisms by which this empowerment happens. They maintained that “Individual

empowerment is expressed through membership in an organization, relationship building with community members, and practice of action-reflection dialectic through the organizational cycle” (p. 736). In self-help organizations such as family-run organizations, people often join initially needing help but can transform from that role into resources for other people. In the process, they develop reciprocal relationships and a sense of community (Levy, 2000; Rappaport, 1987; Zimmerman, 1990). Scholars have also noted the importance of a “sense of community” in the development and sustainability of individual empowerment (Nelson et al., 2001; Rappaport, 2000).

Family-run organizations can be local, statewide or national. Statewide family-run organizations are funded by the federal Department of Health and Human Services (DHHS) and support family involvement in mental health policy development. The DHHS SOC website reports that there are forty-two statewide Family Networks. The website further describes the function of Family Networks to: Provide information, referral, and support to families of children and youth with or at risk of experiencing serious emotional disturbances and participate in the development of policies, programs, and quality assurance activities related to the mental health of children and adolescents with serious emotional disturbances and their families. The essence of knowledge application is achieving change with the recognition that family members are the best and most effective change agents. (DHHS, SOC website, para. 1)

Family-run organizations and the statewide family networks funded under the SOC for children’s mental health, speak to the commitment of the federal government to the idea of empowerment of families. Family-run organizations under SOC differed from parent organizations in the child disability field, in that, they were not grassroots organizations, per se, but rather organizations formed and mandated by grant requirements; and the majority of women staffing family-run organizations under SOC were low-income women (Black and White) needing publicly funded services. These

important differentiations show that, throughout history, social policy for addressing poverty emerged from the values and moral philosophy of the creators of the policies (Dobelstein, 1999). This differentiation may also be part of the reason for the current state of family-run organizations under SOC.

There is a paucity of literature on family-run organizations under SOC. The federal government, through SOC grant funds, mandated family voice and funded emerging family-run organizations for the terms of SOC demonstration grants. However, this mandate lacked the necessary details about the philosophical grounding and the long-term intended outcomes of parent participation on families and the service system. In addition, the responsibility to continue funding for family-run organizations was left up to the states. Evaluation data on the sustainability of family-run organizations as a model for parent empowerment appears absent. Yet, as a condition of receiving funding, all SOC grantee sites must participate in a national evaluation conducted by a third-party evaluator. Absent from this evaluation has been the collection of information on the experiences of parents staffing family-run organizations, the effect of family organizations on the parents who staffed them, and the continued work of parents after the grants end. In short, federal funds for SOC continue to include family-driven language but fail to evaluate family-run organizations.

This dearth of evaluation data creates a gap in the literature on how best to implement the family-run organization component of SOC grants, as well as on the impacts of this component on parents, their children, other parents, and the system at large. In 1996, Briggs attempted to explain this lack of literature: “1) national, state, and

local family organizations have only started within the last 10 years and 2) family support programs in children's mental health are relatively new" (p. 449). However, 17 years after this article was published, the research on family-run organizations remains sparse. What we do know is not encouraging. The literature confirms my observation that family-run organizations cease to exist when grants reach their end dates and so, too, do the influx of federal funds. Research on the 1993–1994 SOC sites demonstrated that the principle of family involvement was only moderately implemented during the grants and showed slippage after the grants ended (EvalBrief: Systems of Care, 2004). Stroul and Manteuffel (2007) studied SOC grant sites that had completed their federal funding cycles. Their research revealed several key findings related to parent involvement in SOC activities. These researchers reported that supportive services to families as well as the number of parents participating in systems reform had declined significantly. Not surprisingly, the sharpest decline was among family-run organizations. Additional research on SOC sites demonstrated that the principle of family involvement followed the same downward trajectory. This principle of parent partnerships, which was never fully implemented during grant funding, declined sharply post- funding (EvalBrief, Systems of Care, 2004). The national evaluation of SOC sheds no light on these findings about parent involvement in staffing family-run organization or about the role of these organizations in impacting services for children.

### **Overview of Theoretical Traditions that Inform this Study**

In this study, I examined the perceptions of empowerment held by parents who were running family organizations under SOC in a single state located in the United

States. As described earlier in this chapter, the majority of people who use publicly funded human services in the U.S. are women with children. Publicly funded human services are hierarchical, with the power firmly entrenched in the hands of providers. The service system for children's mental health reflects this pattern. These two salient issues underscore the roles of both feminist theory and empowerment theory as the theoretical traditions that inform this study. Both of these frameworks have shaped its epistemology, my research methods, and my analysis.

I chose feminist theory and empowerment theory as the conceptual frameworks for my doctoral project because both of these theories focus upon ameliorating oppression for marginalized populations through the enhancement of personal power, advocacy for social change, and reduction of oppressive systems (Cosgrove &McHugh, 2000). These theories are associated with the reduction of oppression through the acquisition of personal power. Through knowledge and skill acquisition that results in agency, the ability to purposefully direct one's actions emerges. A brief review of both of these conceptual frameworks follows.

### **Feminist Theory**

A rich, deep, and broad body of work supports feminist theory (Cacoullos, 2001). My intent is not to review all of the major strands of feminist theory in this dissertation but to support the use of feminist theory as a conceptual framework for this study. Feminist theory examines the practice of power imbalance resulting in the oppression of women based on their gender, which Cudd (2006) contended is "the longest standing case of oppression" (p. 224). To further my point, I draw from Villaverde (2008), who wrote



that “. . . how power is exercised and experienced is central to feminist pedagogy and discourse” (p. 123).

Feminist theory is not a singular concept or philosophical strand, but rather encompasses multiple distinct approaches to understanding the oppression of women. Saulnier (1996) categorizes the different divisions of feminist theory as liberal, radical, socialist, lesbian, cultural, African-American, postmodern, and global. Each of these perspectives approach women as an oppressed group but attribute this oppression to different causes. The strategies to ameliorate women’s oppression vary and include advocating for change in social structures and economic conditions through political action and by dismantling male-dominated power structures. Other strategies for alleviating women’s oppression include infusing women’s values into current power structures, raising consciousness, separating women from men, and honoring women’s stories (Abramovitz, 1996; Dietz, 2003; Saleebey, 1994).

A salient feature of feminist theory related to the oppression of women is the silencing of women’s voices. One way to mitigate that oppression is the amplification of women’s voices in ways that speak to their experiences. Crary (2001) contended that, “. . . feminist theory often presents itself as a vehicle through which women can find their voice” (p. 375). Women’s voice and knowledge are related to their position in the social stratum. Through this position, women interpret the world idiosyncratically and develop knowledge from these interpretations. We can begin to understand the viewpoints of women when we listen to women tell their stories, from their perspectives (Collins, 1989 & 1991).

Voice often leads to agency. For the purposes of this dissertation, I am using Ahearn's (2001) definition: "Agency refers to the socioculturally mediated capacity to act" (p. 112). To expand on this thin definition, Kabeer (1999) added that the capacity to act, (e.g., agency), carries with it the "meaning, motivation and purpose with which individuals bring to their action" (p. 438). Villaverde's (2008) definition of agency added richness by extending the definition to include the "ability to negotiate complex power relationships" (p. 2). Villaverde (2008) further contended that knowledge alone is insufficient to produce change, for without agency (i.e., the ability to negotiate complex power relationships); the systemic forces of hegemony become overwhelming. When women resist the scripts, roles, and functions ascribed to them through the dominant cultural narratives, they are practicing a form of agency (Banks-Wallace, 1998). Resistance, therefore, is a form of agency.

Current feminist writers understand female oppression through the different lenses of race, class, sexual orientation, and/or the historical nature of all of the above (Cacoullos, 2001; Saulnier, 1996). However, this was not always the case. During the 1960s and 1970s, a chasm emerged in feminist thinking around the exclusion of women of color, who were largely ignored in feminist thinking, research, and writing. From the resultant attention to Black feminist thought, new theories emerged; for example, the multiracial feminist theories that examined the interconnection of multiple inequalities such as gender, race, class, and sexual orientation. What transpired produced a new understanding of the implications of differences in the oppression of women. New concepts emerged that advanced the understanding of oppression. Some of these

concepts include the acknowledgement of intersectionality of race, gender, and class (Collins, 1989) and that position within a hierarchy creates standpoints that differ from each other and are unique (Collins, 2000; Edmonds-Cady, 2009; Swigonski, 1994). Enns (2010) described intersectionality in greater detail when she wrote:

In general, women of color feminisms: (a) raise consciousness about the inadequacies of narrowly defined social and civil rights movements, including feminist approaches; (b) debunk stereotypes relevant to specific groups of women; (c) document the multidimensional identities and oppressions of women of color as well as within-group diversities; (d) enumerate survival skills, agency, and resilience shown by women of color . . . (p. 334)

Standpoint is another important concept that emerged from the post-1970s feminism and bears relevance to the present study. Our location or positionality is our place in the social hierarchy. This informs our opinions, actions, and our standpoints (Harding, 1997; Swigonski, 1994). A standpoint is the knowledge gained by people outside of the mainstream as they experience daily struggles with “power relations inherent in the historical social locations that each occupy” (Edmonds-Cady, 2009, p. 12). This standpoint gives a unique, “outsider” perspective on the nature of a particular form of domination or a particular power imbalance. Swigonski (1994) summed this up when she wrote, “Standpoint theory begins with the idea that the less powerful members of society experience a different reality as a consequence of their oppression” (p. 390). To understand this “different reality” we must first begin with women’s epistemology—their ways of knowing the world based upon their experiences as women (Crary, 2001).

Feminist theory also identifies with the empowerment of women across many domains, including social structure, economic conditions, and political action. The

system of human services has a role to play in each of these. In the human-services systems in which eligibility is determined by poverty status, women with children are overrepresented. The paternalistic structure creates dependency through the withholding of valued resources if women fail to conform to paternalistic policies (Nuebeck & Cazenave, 2001). These paternalistic policies determine the code of conduct for women and sanction women who fail to meet these standards (Katz, 1996). Even though feminist theory helps explain the need for empowerment in human service systems, the adoption and adherence to an empowerment approach remain mired in the problematic and exclusionary mechanisms that govern the systems. Feminist theory helps us understand the gendered context of women's lives and the reasons why patriarchal systems remain mired and problematic. This understanding is in itself an empowering process.

Feminist theory is an appropriate framework for this study because the majority of the study participants were women with low incomes. Moreover, the study is about giving voice and agency, a process that directly correlates with both interpretive phenomenology and empowerment. Feminist theory aids the exploration of power differentials in terms of gender, race, and class. It also explores the intersectionality of these constructs, which can have a multiplicative effect that results in the greater disempowerment of women who belong to certain groups. These are salient issues in seeking to understand how women interpret their lived experiences staffing a family-run organization that is designed to give them voice, agency, and political understanding. Feminist theory addresses the issues of women's agency and voice as it relates to their

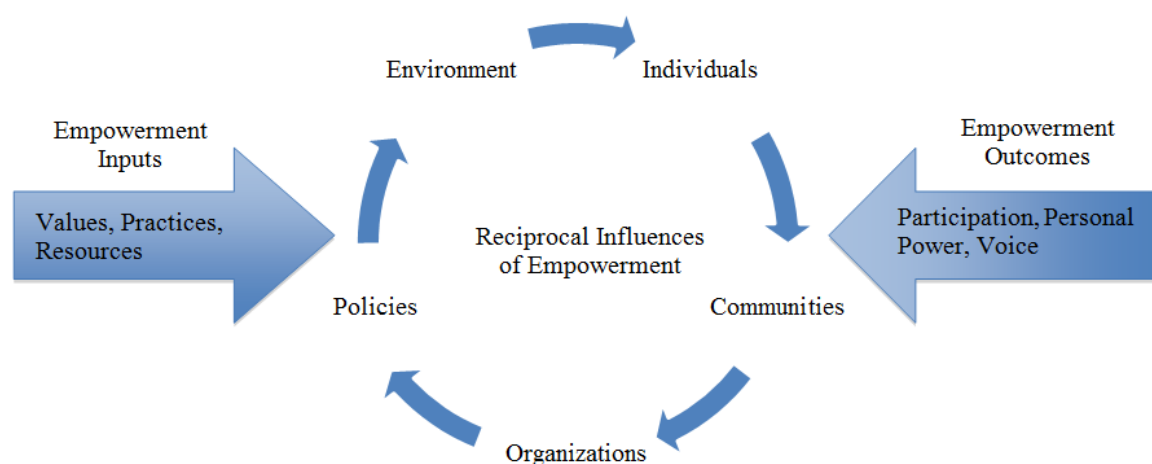
position in the social hierarchy. Last, feminist theory addresses the negative myths surrounding women who attempt to access public health services (Enns, 2010).

Even in this brief review, what become clear is the acknowledgment and importance of the continued growth and variability of what constitutes feminist theory. As Dietz (2003) wrote: “Thus, what really exists under the standard rubric of feminist theory is multifaceted, discursively contentious field of inquiry that does not promise to resolve itself into any programmatic consensus or converge onto any shared conceptual ground” (p. 400). The theme that remains consistent throughout this “discursively contentious field of inquiry” (p. 400) is language that references emancipation and empowerment, which speaks to the aim of eradicating oppression of women (Dietz, 2003).

### **Empowerment Theory**

Feminist theory describes women’s conditions outside of the power structure. At the core of empowerment theory is the root word “power.” Like feminist theory, empowerment theory is concerned with alleviating the condition of disempowerment through enhancing people’s ability to claim their power and act on their own behalf. Since the early 1990s, empowerment as a concept, theory, and intervention has been deconstructed to understand its complexity more fully (Fawcett et al., 1995; Zimmerman, 1995). Empowerment theory has been applied to individuals, communities, and organizations (Shulz, Israel, Zimmerman, & Checkoway, 1995). It encompasses empowerment values and processes that impact individuals, communities, organizations, and the environment (Boehm & Staples, 2002; Drake, Wong, & Salter, 2007; Fawcett et

al., 1995; Perkins & Zimmerman, 1995; Sadan, 1997; Seibert, 2006; Teixeira & Menezes, 2009; Zimmerman, 2000). This emphasis, in turn, can lead to empowerment outcomes across these same domains (Koberg, Boss, Senjem, & Goodman, 1997; Perkins & Zimmerman, 1995). These processes and outcomes are depicted in Figure 1.



**Figure 1. Empowerment Theory Processes and Outcomes.**

At the core of empowerment is the belief that all people have strengths and capabilities (Rappaport, 1981; Saleebey, 1992). This foundational belief countermands the dominant cultural narrative that describes many people as innately flawed due to their gender, race, class, or combination of these. Through empowering processes, strengths and capacities are identified, exercised, and further developed. Strengths are identified as resources that people have to overcome life's challenges. Saleebey (1992) noted that the identification and narration of "personal and cultural stories" (p. 51) is a strength that contributes to empowerment.

Empowerment theory, which informed my discussion of empowerment earlier in this dissertation, always describes a movement toward gaining greater power and ability

to control one's life (Rappaport, 1984, 1987; Sadan, 1997). Sadan expanded upon this further when he wrote, "The [empowerment] process is aimed at changing three dimensions of a social condition—to bring about a change in people's feelings and capacities; the life of the collective that they belong to; and the professional practice that gets involved in the situation" (p. 13). Many scholars concur that empowerment is a process (Gutierrez, 1990; Kieffer, 1984; Nelson et al., 2001; Rappaport, 1987; Sadan, 1997; Wallenstein, 1992). Zimmerman (1995) described empowerment as . . . a series of experiences in which individuals learn to see a closer correspondence between their goal and a sense of how to achieve them, gain great access to and control over resources and where people, organizations and communities gain mastery over their lives. (p. 583)

The process of empowerment is not linear but rather unfolds in different ways for different people (Gutierrez, 1984; Zimmerman, 1995). Understandably, the intangible nature of the process of empowerment makes it difficult to measure and quantify. This difficulty results in a multiplicity of meanings across and within people, organizations, and communities (Foster-Fishman, Salem, Chibnall, Legler, & Yapchai, 1998; Rappaport, 1987; Zimmerman, 1995). In addition, empowerment is viewed through an individual's perceptions (Peterson & Speer, 2000) which in themselves are hard to objectify.

Psychological empowerment refers to empowerment at the level of the individual. Individual empowerment is the most-studied component of empowerment (Rappaport, 1987; Zimmerman, 2000) and the one most often referred to as a desired outcome in the human service delivery system. It is the outcome whereby recipients gain greater self-

efficacy, knowledge, and behaviors that allow them to participate as equal partners in the services they receive. Although researchers have made the case for a link between empowerment processes and empowerment outcomes (Perkins & Zimmerman, 1995), little attempt is made in human services to delineate these links. Empowerment of participants in services leads to better physical and social outcomes and decreased dependence upon formal service-delivery systems.

“Individual empowerment” is the term I use throughout this dissertation.

Individual empowerment refers to a person gaining greater control over his or her environment through a shift in thinking, gaining awareness, and adopting new behaviors (Rappaport, 1984). “Empowerment conveys both a psychological sense of personal control or influence and a concern with actual social influence, political power and legal rights” (Rappaport, 1987, p. 121). Every individual defines empowerment as it relates to his or her own life. For this reason, and because empowerment is context-specific, each of us understands empowerment differently. Individuals’ understandings are shaped by their perspectives and lives (Foster-Fishman et al., 1998; Rappaport, 1987; Zimmerman, 1995, 2000). Feeling empowered encompasses two components: (a) the acquisition of real power and control; and (b) the perception of power and control (Nelson et al., 2001).

Individual empowerment consists of three dimensions: interpersonal, interactional, and behavioral (Shulz et al., 1995). Zimmerman (2000), a leading scholar on empowerment, added a another layer to these three components by proposing (as did Rappaport, 1987, 1995) that the interpersonal component of individual empowerment refers to beliefs about perceived control that are represented by a sense of self-efficacy as



well as the ability and competence to control resources and influence decisions about one's life. The interactional component of individual empowerment suggests that an individual develops interdependent relationships that enhance his or her ability to access resources, negotiate with people in power, and navigate systems. Zimmerman (1995, 2000) further described the behavioral component of individual empowerment as the culmination of the other components that results in an individual taking action, based upon personal beliefs and choices, to enhance his or her life circumstances (Zimmerman, 1995, 2000). Behavioral action can happen either individually or as part of a group or organization. Zimmerman (2000) summed up individual empowerment when he wrote, "Empowered individuals have some combination of sense of control, critical awareness of their sociopolitical environment and involvement in their community" (p. 50).

To summarize, feminist and empowerment theories are similar in many ways. Both of these theories address the reduction of alienation and marginalization through the claiming of personal power and voice. Moreover, these two constructs have frequently been linked in the literature (Bond, Belenky, & Weinstock, 2000; Browne, 1995; Lazzari, 1991; Morell, 2003). The constructs in feminist theory and empowerment theory that relate to this study are (a) identity formation (Groleau & Zelkowitz, 2009), specifically, identifying oneself as empowered (Zimmerman & Perkins, 1994); (b) voice, defined as the ability to identify your location in the social strata and speak from your position about your position (Collin, 1989); and (c) agency, which means taking measures to change one's current situation through self-directed actions (Ahearn, 2001; Kabeer, 1999; Villaverde, 2008). Both feminist and empowerment theories share the underlying

assumption that people are located within their social strata due to sociopolitical structures and policies. Where these theories diverge is on the population of focus. Feminist theory addresses the marginalization of women and examines the world through a gendered lens, whereas empowerment theory encompasses all marginalized populations. Furthermore, feminist theory applies to a group of people (i.e. all women). Although empowerment theory has been applied to groups of people, its most common application is at the individual level (Zimmerman, 2000).

### **Conclusion**

In this chapter, I have reviewed the salient literature on the roles of power, gender, race, and class on the human-service system in the U.S. and have highlighted the implications of stories in all their forms, including dominant cultural narratives. In this chapter I have also traced the evolution of the parent movement and the differences between its success and the successes of the grassroots parent movement for children with disabilities that was started and staffed by White, middle-class women (Groce, 1996) as well as the parent movement under SOC, which was started by professionals and was staffed mostly by low-income women of different races. Last, I have briefly reviewed the two theoretical traditions that inform this study: (a) feminist theory; and (b) empowerment theory. In Chapter III, I shall summarize the research methodology that I utilized in this study and demonstrate how this methodology is consistent with both of the underlying theories.

### **CHAPTER III**

#### **STUDY METHODOLOGY**

The purpose of this study is to understand the lived experience of parents as they staffed family-run organizations under SOC grants in a single state in the United States, through their own voices. Serrano-Garcia and Bond (1994) contended that the ability to have a voice that is “heard” is an important part of the empowerment process for marginalized groups. Having voice also helps parents make sense of these experiences as they reflect upon and share their stories (Patton, 2000). In this study, I explored the extent to which the program model of family-run organizations aids perceptions of empowerment among the participating families and the extent to which such perceptions of empowerment are sustained after grant funding has ended. In addition, I examined the gendered context in which these parents, all of whom are female, live. Last, this study is intended to generate questions for further research and to highlight implications for practice.

#### **Research Questions**

The three specific research questions that guided this study were:

1. How do parents or caretakers raising children with mental illness and staffing family-run organizations under SOC funding describe and make sense of their lived experiences before and during their involvement with the organizations?

2. How are these perceptions gendered, and how does their gendered nature reveal ways that participants' roles as women are salient?
3. How can the lessons learned from these parents inform the model of family-run organizations under SOC that are staffed primarily by low-income mothers?

These research questions create context for my interpretations of the stories that parents shared in their own voices and their own words.

### **Qualitative Research Design**

I used a qualitative, interpretive, phenomenological research method for this study. This method provided the lens and structure for data collection, analysis, and interpretation through which I attempted to understand the phenomenon of parents who staffed family-run organizations under SOC. In this section, I provide an overview of qualitative inquiry followed by more specific details on phenomenology as a philosophy and its transition to a research methodology. Last, I provide specifics on conducting an interpretive phenomenological study and describe the application of these concepts to my study.

Qualitative inquiry is a form of research and evaluation that immerses the researcher in the context of the study in order to ascertain the findings. It is different from, but complementary to, quantitative research. Through qualitative studies, we come to understand complex human phenomenon from an interpretive perspective (Draper, 2004; Nicholls, 2009). Draper (2004) defined qualitative research as being concerned with “the quality or nature of human experiences and what those phenomena mean to

individuals” (p. 642). Denzin and Lincoln (2005) further described qualitative analysis as “an intimate relationship between the researcher and what is studied” (p. 10) that allows us to capture the meaning of an event or events. O’Connor and O’Neill (2004) contended that qualitative research “fosters a rebalancing of power between researcher/researchee relationship and focuses on marginalized understandings and experiences” (p. 19). Studies with an empowerment focus are well suited to qualitative research methods (Rappaport, 1995; O’Connor & O’Neill, 2004).

Creswell (2007) described the philosophical assumptions that researchers make when choosing what to study according to a matrix that outlines five assumptions, the questions associated with those assumptions, the characteristics of the assumptions, and the implications for practices. To illuminate my own assumptions further, I have reproduced Creswell’s matrix (see Table 1) and added relevant data (in italics) on how my study relates to each assumption.

**Table 1. Research Assumptions**

Assumption	Question	Characteristics	Implications For Practice
Ontological	What is the nature of reality?	Reality is subjective	Research uses, quotes/themes, and participants’ words
	<i>This study attempts to understand the reality of parents who were working in family organizations funded under the federal System of Care grants for this state.</i>	<i>Questions to participants include the nature of parents’ experiences working in family organizations. Each participant is asked similar questions, but the nature of their responses correlate to their lived experience.</i>	<i>Common themes from the recorded interviews are the source of data. These themes are grounded in the quotations from and words of the participants.</i>

Table 1. (Cont.)

Assumption	Question	Characteristics	Implications For Practice
Epistemological	<p>What is the relationship between the researcher and participants?</p> <p><i>In this study, I know all of the participants.</i></p>	<p>Researcher closes the gap between herself and the participants.</p> <p><i>I am considered a “supporter” by some of the participants.</i></p>	<p>Researcher collaborates, spends time in the field, and becomes an “insider.”</p> <p><i>I have worked alongside most of the participants in the study. For many years I provided technical assistance and support as the participants grappled with maximizing their roles in family-run organizations.</i></p>
Axiological	<p>What is the role of values?</p> <p><i>Values are critical to every aspect of this study, from my perspective as the researcher and from those of the participants.</i></p>	<p>Researcher acknowledges that research is value-laden and that biases are present.</p> <p><i>My beliefs and values are part of the driving force for choosing this research study. They are explicitly stated within the research study.</i></p>	<p>Values that shape the narrative are openly discussed, as are interpretations by the researcher and the participants.</p> <p><i>My values are discussed throughout the study. The researcher and the participants discuss how these values shape the interpretation of the results.</i></p>
Rhetorical	<p>What is the language of research?</p> <p><i>The language of this study is personal and easy to read.</i></p>	<p>Researcher writes in an informal style using the personal voices using qualitative terms.</p> <p><i>The informal style of language and the lack of jargon are purposeful. Not only is this consistent with the requirements of qualitative research, it is also necessary in order for the participants to read and understand what I have written about their stories.</i></p>	<p>Researcher uses and engaging style of narrative and may uses the first-person pronoun</p> <p><i>This research study is personal because it is infused with my values and beliefs that undergird all of its aspects. The results, although dependable, are uniquely mine.</i></p>

**Table 1. (Cont.)**

<b>Assumption</b>	<b>Question</b>	<b>Characteristics</b>	<b>Implications For Practice</b>
Methodological	<p>What is the process of research?</p> <p><i>This qualitative study uses semi-structured interviews as the primary method of data collection.</i></p>	<p>Researcher uses inductive logic, studies the topic within its context, and uses and emerging design approaches.</p> <p><i>After the literature review and a personal review of my experiences with the participants, a series of open-ended questions was asked. This series was designed to expose common themes.</i></p>	<p>Research works with details before generalizations, describes in details the context of the study.</p> <p><i>The questions are fluid and open to revision. After the first round of interviews, I realized that I should be asking slightly different questions. I revised the questions and conducted another round of interviews.</i></p>

### **Phenomenology**

Phenomenology is a movement rather than an exact discipline (Gearing, 2004; Lopez & Willis, 2004; Rappaport & Wainwright, 2006). As phenomenology continues to evolve, a codified definition or unified interpretation is difficult to find (LeVasseur, 2003; Lester, 1999). There is, however, agreement on the primary objectives of phenomenology. Scholars describe these objectives as the investigation, reflection, interpretation, and description of a phenomenon as consciously experienced by those who live it (Creswell, 2007; Dowling, 2007; Smith, Flowers, & Larkin, 2009).

Phenomenology emerged from the field of philosophy and shares a link to the natural sciences (Dowling, 2007; Gearing, 2004). More recently, phenomenology has developed into a qualitative scientific research method that adds both value and confusion to qualitative research endeavors.

## **Phenomenology and Philosophy**

The roots of phenomenology are firmly embedded in the history of philosophy, as far back as Socrates and Plato (Dowling, 2007; Gearing, 2004). In early twentieth century, phenomenology re-emerged among German philosophers as a conceptual way of thinking about the origins of knowledge (Dowling, 2007; Walters, 1995).

Phenomenology continued to branch out into different schools, starting with the German school that most notably included Edmund Husserl (1859–1938) and Martin Heidegger (1889–1976), and the French school with such notable contributors as Sartre (1905–1980) and Merleau-Ponty (1908–1961). Many other philosophers and scholars have added to our understanding of phenomenology.

To lay the foundation of my study, I provide a brief overview of the philosophical underpinnings of phenomenology through the lens provided by Husserl and Heidegger, two of the earliest and most prominent scholars in the field. The work of these two forerunners provides the contextual backdrop for my choice of research methodologies. In contrast to the European movement, America came late to the phenomenology movement. It was during the 1970s that phenomenology became a subject of interest in America; with this new interest emerged the “new phenomenology” that quickly morphed into a research methodology based on earlier philosophical traditions (Crotty, 1996; Dowling, 2007; Groenwald, 2004).

Husserl is the acknowledged founding father of the phenomenology movement (Dowling, 2007, Koch, 1996). This scientist, mathematician, and philosopher made the early link between phenomenology and science (Gearing, 2004). Writing in the early



twentieth century, Husserl concentrated on developing a scientific formula that described the origins of knowledge (Walters, 1995). Much later, Husserl (1983) refuted the naturalist approach to science and proposed that the lived experience was the basis for all knowledge.

Husserl believed that the origin of knowledge and truth is inherent in our own lived experience and that truth can be derived through thinking, remembering, and perceiving as we experience conscious acts (Smith et al., 2009; van Manen, 1984; Walters, 1995). Giorgio (2005) wrote that Husserl “reasoned that anything that had to be dealt with in the world had to come through consciousness” (p. 76). Conscious acts are experienced around tangible objects, such as a house, or intangible objects, such as a memory (Giorgio, 1995; Smith et al., 2009; van Manen, 1984). This concept of experiencing conscious acts is known as intentionality (Shionoya, 2010). Intentionality includes both process and object. Through intentionality, we are “always conscious of something” (Smith et al., 2009, p. 13). Intentionality is important because it “shifts the focus from physical nature, cause and effect analysis . . . to human subjectivity, intentionality, meaning of actions and the freedom and responsibility that intrinsically belongs to them” (Giorgio, 2005, p. 77).

Intentionality requires a shift in mindset. To evoke intentionality, Husserl proposed that we must first put aside our preconceived ideas and knowledge about conscious events, a practice called he called “bracketing” (Gearing, 2004; Lopez & Willis, 2004; Smith et al., 2009; Walters, 1995). Bracketing requires us to “bracket out,” as in a mathematical equation, prior knowledge that would block our ability to completely

understand the nuances of our lived experiences (Smith, Flowers, & Larkin, 2004). In other words, bracketing allows us to ignore and refrain from interpretations that would cloud our ability to understand the essence of phenomena. However, as intriguing as the concept of bracketing appears, Husserl never fully describes it, nor did he describe how one would actually bracket out known information (Gearing, 2004). Husserl also proposed a process called eidetic reduction, which is the ability to reduce and recall phenomena as they are observed and described, not as they are interpreted (Kellett, 1997; Rappaport & Wainwright, 2006). In this descriptive methodology, the roles of culture or context were not considered relevant, or important, in understanding the essence of lived experience (Lopez & Willis, 2004; Wojinar & Swanson, 2007). From Husserl's work emerged a significant cultural movement that attracted prominent followers such as Heidegger.

Heidegger both admired and diverged from Husserl's views (Lopez & Willis, 2004). As a student of Husserl's, Heidegger was another early contributor to the philosophy of phenomenology. He agreed with Husserl that experience was the origin of knowledge; however, he approached how that experience is to be understood from a different framework. In his seminal book, *Being and Time* (1963), Heidegger espoused upon his primary interest, which he referred to as *Dasein*, a German word for "being" that to Heidegger meant being aware of our own existence in the world (Mackey, 2005; Smith et al., 2004). As Kellett (1997) wrote, "He [Heidegger] believed that the primordial given 'I' (self) was already part of the world" (p. 60). This primordial self encompasses more than just being, and can be broadened to think about the concept of

“what it means to be” (Kellett, 1997). van Manen (1984) further described Heidegger’s notion of being as the way humans act, exist, or are involved in the world. According to Mackey (2005), “One of Heidegger’s central tenets was that existence is embedded in-the-world and our being in-the world cannot be separated from the world” (p. 181).

Therefore, understanding the context, culture, and time in which an event occurred are all critical to the understanding and interpretation of a phenomenon (Campbell, 2001; McConnell-Henry, Chapman, & Francis, 2011). Heidegger believed that the study of “being” was more necessary than the study of consciousness proposed by Husserl (Moran, 2000). Rather than relying only upon description of the lived experience, Heidegger focused on interpretation as a primary means of understanding a phenomenon (Lopez & Willis, 2004). This means, of course, would preclude the uses of bracketing and eidetic reduction proposed by Husserl.

The emergence of phenomenology as a philosophy represents an important epoch. Through its emphasis on human subjectivity, consciousness, and intentionality, it challenged current notions of the natural sciences, cause and effect, and empiricism. It expanded thinking about the origins of knowledge and challenged the prevailing truths of its time. It opened the doors to greater understanding of science and knowledge and paved the way for related research methodologies.

### **Phenomenology and Research**

Phenomenology as a qualitative research method gained popularity in the 1970s (Crotty, 1996; Dowling, 2007; Groenwald, 2004). Because phenomenology evolved from philosophy, via contributions from multiple schools and contributors, to become a

research method, it is easy to understand why differentiating the exactness of phenomenological research can be challenging. When Crotty (1996) described the new phenomenological research, he referred to its subjective nature and its focus on how those who are experiencing phenomena understand their meanings and significance. Valle and Halling (1989) offered a similar description of phenomenological research, but with different nuances. They described phenomenological research as “the rigorous and unbiased study of things as they appear so that one might come to an essential understanding of human consciousness and experience” (p.10).

Despite the variety of its forms and definitions, phenomenological research is quite popular, particularly within health sciences and nursing studies (Bradbury-Jones, Irvine, & Sambrook, 2008; Dowling, 2007; Salmon, 2012). Phenomenology as a research method receives criticism for comingling the science of philosophy and the practice of research in sometimes incoherent ways as well as for the lack of methodological congruence and rigor in some research studies (Dowling, 2007; Mackey, 2005; Walters, 1995). Despite these criticisms, it is possible to conduct rigorous qualitative research using a phenomenological method. To increase rigor, one must first identify the phenomenological approach that will be used and the rationale for this approach must align with the study being undertaken (Mackey, 2005; Walters, 1995). The method of analysis is also critical. When the philosophical underpinnings are well articulated and align with well-defined methods, a phenomenological approach can be an appropriate method for qualitative research (Pringle, Drummond, McLafferty, & Hendry, 2011).

Two of the most common forms of phenomenological research draw from the philosophies of Husserl and Heidegger (Dowling, 2007; Flood, 2010; Mapp, 2008). Generally, studies that use a more Husserlian approach are more descriptive (Mackey, 2005), apply the concept of bracketing (Lester, 1999), and are not concerned with the roles that culture and context play in understanding a phenomenon (McConnell-Henry et al., 2011). Heideggerian studies generally adopt interpretative stances (Lopez & Willis, 2004; Mackey, 2005; Smith et al., 2004). Interpretive phenomenological research projects grounded in the Heideggerian school share the beliefs that bracketing prior knowledge is not necessary or possible (Haggman-Laitila, 1999); the researcher's own experience and knowledge of the subject are relevant (Walters, 1995); a keen eye to the cultural embeddings of the participants are critical (McConnell-Henry et al., 2011); and the interpretations reached are "a fusion of the views of the researcher and the participant" (Haggman-Laitila, 1999, p. 13).

For this study, I have chosen to use an interpretative phenomenological approach and detail the appropriateness of this choice later in this chapter. In the next section I highlight the key components of interpretive phenomenological research, including background, role of the researcher, sample size, data collection, and analysis.

### **Interpretive Phenomenology as a Research Method**

The interpretive phenomenological research emerged from the Heideggerian school of phenomenology. This form of research provides a mechanism for looking at common life experiences and by which to understand those lived experiences (Jones, 2001; Pringle, Drummond, & McLafferty, 2010). This mechanism primarily involves

dialogue with people who have lived a particular experience; thus, it privileges the voices and experiences of participants. Mackey (2005) summed up the power of interpretive research when she wrote:

The interpretive approaches allows for research which aims for understanding, rather than explanation of human phenomenon; for research which is conducted in a natural uncontrolled setting; and for research which utilizes the knowledge embedded in the experience. (p. 179)

A basic tenet of interpretive phenomenological research is that knowledge is created as each individual tells a story about an experience (Haggman-Laitila, 1999; Moran, 2000). Through interpretation, the truths of the experience emerge. Truth in this context is used as a plural because there can be many truths about a lived experience and all truths are person- and context-specific (McConnell-Henry et al., 2011).

### **Role of the Researcher**

Scholars support the claim that the researcher's personal knowledge of the phenomenon under study is critical in interpretive phenomenological studies (Smith, Flowers, & Larkin, 2009). This claim is quite different from the tenets of qualitative studies and of many quantitative studies as well. However, because the researcher is responsible for interpreting the data, the more knowledge he or she has about the phenomenon, the better the likelihood of a more-accurate interpretation. A detailed discussion of the possible influence that my own experiences may have had on the results of this study and how I attempted to eliminate my bias can be found in the section of this dissertation in which I describe the specifics of my study.

### **Sample**

According to interpretive phenomenological standards, participants must be purposely selected to include people who have lived the phenomenon under study (Smith et al., 2009). Generally, the sample size is small, between three and six participants (Larkin, Watts, & Clifton, 2006; Smith, 2004; Smith et al., 2009). The sample size is purposefully limited due because of the detailed analysis needed for each participant (Smith et al., 2009). My sample size of eight participants, although slightly larger than the size recommended by Smith et al. (2009), was within acceptable limits.

### **Data Collection**

Data collection for interpretive phenomenological study is usually conducted via an unstructured or semi-structured interview (Mapp, 2008). As Smith et al. (2009) described, an interview “is a conversation with a purpose” (p. 57). Interviewers use a guide, but try to set up the conversation so that the interviewee talks freely. The interviewee and researcher should guide the interview together. These types of prompts assist the process of gathering rich data. Interviews, which often last 60 to 90 minutes, include prompts such as “Tell me more,” and “Can you explain that further?” (Smith et al., 2009; Webb, 2003). Once the participant begins to repeat him or herself, saturation has been reached and the interview should end (Mapp, 2008). My interview guide (see Appendix A) was approved by the Institutional Review Board of the University of North Carolina at Greensboro.

### **Analysis of Interpretive Phenomenology**

As previously mentioned, phenomenological studies have been criticized for their lack of congruence between philosophical underpinnings and data analysis. To mitigate these criticisms, I relied extensively on the work of Smith et al. (2009). I chose the work of these authors to guide my thinking about data analysis because they are widely referenced in other studies and have written a comprehensive book, *Interpretive Phenomenological Analysis* (2012) that details the appropriate steps in interpretive phenomenological research to maintain congruence with an interpretive tradition based upon a Heideggerian philosophy. The analysis sections of qualitative studies are complex and require the ability to both suspend and incorporate the researcher's preconceived notions and voice. They also require the ability to apply inductive reasoning to the data (Thorne, 2000). In data analysis, we must be able to elucidate and connect with what Larkin et al. (2006) referred to as "objects of concern" and as "experiential claims" made by the participants.

Data in interpretive phenomenological studies most often appear in the form of interviews, as was true of my study. For analysis, I read each interview transcript multiple times and examined each on in great depth to obtain a "detailed, nuanced analysis" (Smith, 2004, p. 42). Collection started with a detailed analysis of the text after which the researcher interpreted the text (Peräkylä, 2005; Smith, 2004). Wojnar and Swanson (2007) wrote that data analysis provides the means to "identify the participants' meanings from a blend of the researcher's understanding of the phenomenon, participant generated information, and data obtained from other relevant sources" (p. 175).



Pringle, Hendry, and McLafferty (2011) summarized the steps of data analysis in interpretive phenomenological studies that were provided by Smith et al. (2009). Their summation follows:

- Read transcripts through several times, making notes and comments.
- Identify and label emerging themes and meanings with the text.
- Relate back and link themes to quotes in the text, using a cyclical process.
- Look for potential links between themes that may lead to master/super-ordinate themes.
- Repeat the process with subsequent transcripts.
- Connect/cluster the themes from texts into super-ordinate themes with related subthemes.
- Examine texts more closely for greater depth of meaning and interpretation (p. 15)

Adhering to these steps helps to ensure a methodologically congruent study; however, doing so does not address issues of data trustworthiness and reliability. Because these concepts are frequently applied to other types of qualitative studies, it is worthwhile to explore their role in interpretative phenomenological studies.

### **Appropriateness of Interpretive Phenomenology for the Study**

I studied the phenomenon of parent-run organizations under the federally funded SOC grant program. In this study, I asked parents to share their experiences with, and their stories about, staffing a parent-run organization. Telling their stories helped them to make sense of their experiences and to contribute to the body of knowledge around these

experiences. In addition, talking to me about their experiences shattered their silence and, in turn, helped these parents claim their power (Bloom, 1998). Interpretive phenomenology shares this stance because “researchers acknowledge that the participants are the experts” (McConnell-Henry et al., 2011, p. 33) in their own lives.

### **Trustworthiness**

Qualitative researchers in the positivist tradition have well-defined methods of validating a study’s results as trustworthy and, to some extent, theory-producing and replicable. These methods often include member checking and data triangulation (Patton, 2002). However, these same concepts do not apply to interpretive phenomenological studies, partly because they are not trying to create theory or generalize their results. The goal of interpretive phenomenological research is to understand the lived experience of a person-in-context. According to Larkin, Watts, and Chilton (2006):

The important point is that our success as phenomenologists will not be dependent upon finding the “pure” experience of the participants; it will be dependent upon being prepared to do the most sensitive and responsive job we can given our inherent epistemological and methodological limitations. (p. 108)

Each participant’s story represents a truth unique to that person that is embedded in his or her context, culture, and time; truth exists according to how participant and researcher understand it. Interpretive phenomenological studies always depict the understanding between two people: the participant and the researcher. This understanding is not applicable across studies; nor can it be generalized to any other person, group of people, or setting (Haggman-Laitila, 1999). As Larkin et al. (2006) wrote, “As analysts we focus in on the person-in context (a particular person in a

particular context) and the person's relatedness to the phenomenon at hand" (p. 109).

Becoming personally engaged in data collection allows the researcher to develop a "deep, richly textured understanding of people under study, which facilitates the understanding of the human behavior observed" (Patton, 2002, p. 49).

### **Reflexivity**

In qualitative research, the researcher must acknowledge and attend to his or her subjectivity. In interpretive phenomenological studies, however, researcher and participants co-create the knowledge and it is the researcher who, when he or she interprets the data, raises new issues of researcher bias and data trustworthiness. Reflexivity is the tool commonly employed in interpretive phenomenological studies to prevent undue interviewer bias throughout the interpretation. According to Swinson (2007), "The researcher must constantly be reflective and open to challenging his other personal knowledge to remain true to the data" (p. 181).

### **Study Location**

I chose a single state in the U.S. as the geographic location of this study for several reasons. First, this state benefited from several federally funded SOC grants that held parent-run organizations as an essential component. Second, I was a consultant to SOC sites and therefore have first-hand knowledge of the implementation process for all SOC grants. In addition, I have, or have had, relationships with the parents eligible to participate in this study. Last, I believe that this state, with its rich history of SOC grants and the geographic diversity of parents throughout the state who have staffed family-run

organizations, has much to contribute to our understanding of parents' experiences both individually and collectively.

The state included in this study received several federally funded SOC grants between 1994 and 2008. Some of the grants covered multiple counties/sites throughout the state and some of the grants served a single county/site. All of these grants received no-cost extensions for one year. This meant that the work could continue for an additional year with the currently allocated funds, but no new federal funds were forthcoming. This year of no-cost extension allowed the grantee sites to use any federal money that had not yet been spent.

### **Recruiting Participants**

As a technical-assistance provider to the family-run organizations in the four grant sites included in this study, I had access to names of and contact information about the parents who participated. From my previous work notes, I was able to identify 39 potential participants. All of these people had staffed parent-run organizations funded with SOC dollars, but the funding for their SOC sites had ended or they no longer worked for the grant site. Of the original pool of 39 parents that I identified, 16 were African-American and 23 were Caucasian. All but three were women.

After I compiled the list of potential participants, I began verifying contact information using the web-based White Pages. This free public website lists personal addresses and phone numbers. It is a national, electronic version of a phone book. Of the 39 names I searched, two had died and I could not find a current address or email address for an additional nine. This reduced the potential list of potential participants to 28. I

sent all 28 of these people the recruitment letter and consent form that the Institutional Review Board at the University of North Carolina at Greensboro had approved. I offered a \$25 gift card in exchange for their participation. In each recruitment package, I included a stamped, self-addressed envelope for the return of the signed consent form. If I had an email address for the participant, I followed up with an email and attached the approved consent form. Of the 28 potential participants, I conducted interviews with 13 people, and eight of these interviews were used in this study.

### **Description of Participants**

At least one person from each grant site participated in the interview process. Of the eight parents I interviewed, all were women. Four were African-American and four of the participants were White. The participants hailed from throughout the state. It should be noted here that not all of the parents were first-generation parents, although the majority did fit this description. First-generation parents are those that were tapped by providers to participate in the initial SOC grant for their locale and start a family-run organization. Second-generation parents were those parents who were recruited and trained by the parents who were already staffing the family-run organization. The terminology of first- and second-generation parents is mine.

### **Interviews**

I held interviews with all eight parents who were deemed eligible on my list of potential participants. All eight participated in an initial interview that lasted between 1 and 1.5 hours, which yielded a total of 15 hours of interview data. Although one interview of 60 to 90 minutes is often sufficient (Smith et al., 2009), I found that a few

participants had only just begun to share their experiences with the phenomenon of staffing family-run organizations by the time we reached one hour. Because I had asked for an hour of their time, I did note when the hour was up, in order to be respectful to their commitment. Almost all of the parents said they could continue for about 30 more minutes. Four parents participated in a second interview of up to 1.5 hours. They had not finished talking about their experiences after the first hour and wanted to finish.

The interview format was loosely constructed and conversational, which allowed the participants to define and elaborate upon their experiences from their own unique perspectives (Bloom, 1998; Brown, 2009). Asking participants open-ended questions allowed them to lead the interviews and helped to minimize the power imbalance between participant and researcher (Bloom, 1998). This practice also allowed the participants to share meanings and interpretations of events and to focus on what was important to them. In my interviews, I used a semi-structured process with some pre-identified questions. The pre-identified questions were only a guide to help elicit the participants' descriptions of their experiences and the meanings of those experiences. I frequently started the interviews with the statement, "I am interested in learning more about your experiences before and during your involvement with SOC." I asked about their experiences before and during involvement with the family-run organizations because I was trying to understand the context that brought them to this work, the context during their work, and any differences of note between the two periods. It was a big task. Although the questions in the interview guide followed a sequential chronology, the interviews themselves did not. Parents spoke about what was important to them. At

times one thought triggered another, and the conversation bounced between their lives prior to and during the phenomenon of the family-run organization.

Although I had a guide to help ensure I touched on key points, for the most part the interviewees shared what was meaningful and relevant from their perspective. I did ask prompting questions as encouraged by Webb (2003) and Smith et al. (2009). At times, I also needed to ask clarifying questions about names and acronyms, or when I was unsure of what I was hearing. I tried to keep my prompting questions to a minimum so they would not interfere with the participants' flow of thought. During the interviews, I also tried to listen with what McConnell-Henry et al. (2011) have referred to as "interpretive intent" (p. 33). This requires recognizing that parents are the experts about their own lives and that I should not jump to conclusions about their statements, despite my personal experience both with the participants and family-run organizations. At times, I found this experience helpful; at other times, through the process of reflexivity, I had to check my thinking against what I had heard. This iterative process was conscious and consistently applied throughout the interviews and subsequent data analysis.

To understand the stories, I listened closely not only to hear their words, but also to feel their emotions and respect their silences. The flexibility in the interview design allowed each parent's unique story to emerge in a way that made sense to them as individuals. These were emotional interviews for the several of the participants and sometimes, for me. Several participants cried as they shared their stories of life prior to SOC. Other parents' physical affect changed as they reflected on their feelings of dejection, anger, or frustration.

Each interview was tape-recorded with the permission of the participant. In addition to the tape recorder, I took copious notes in what I referred to as my “Research Notebook.” This notebook also included my reflections, questions, and memos to myself. After each interview I wrote my impressions, observations, and additional questions in the Field Notes section of my notebook. I am thankful that I had my notebook because during one interview, the tape recorder did not work. Later, I was able to rely upon my notes to reference the discussion.

### **Locations of Interviews**

The ability of the researcher to adapt to each situation contextualizes the process for each individual being interviewed. Creating a setting that honors both safety and trust is critical for a successful interview process (Hoffman, 2007). Participants had the choice of completing this interview via a telephone call or in a face-to-face meeting. If a parent chose a face-to-face interview, she could choose the location that felt comfortable to her. Ultimately I conducted 13 interviews with eight participants in diverse locations, chosen by them. Of these 13 interviews, 11 were face-to-face and two were conducted via the phone. The face-to-face interviews required about 37 hours of car travel. The locations of these interviews included participant’s homes, a coffee shop, resource centers, an office, restaurants, and a hotel lobby. Two of the interviews were conducted via phone. I purchased a conference-call program that allowed me to record the calls for transcription purposes.



### **Data Analysis Methodology**

I tried to follow the outline set forth in Smith et al. (2009) for my data analysis. This process is described in more detail earlier in this chapter. After each interview, I wrote up my field notes. Each audio tape provided rich information; I listened to each one multiple times. Next, all audio tapes were transcribed verbatim and I reread each transcript multiple times. Then I added my field notes at the appropriate points. By this time, I was fully immersed in the data.

The next step of the analysis process involved trying to make sense of the data. I began by numbering the lines of the transcript and creating a wide margin on the left side in which I could write my notes. Initially I treated each transcript as if it were a single case. This meant I did a full analysis on it that included identifying the themes with supporting data. When I thought I had the themes identified, I went back to the data and pulled out the sections of the data that I thought applied to each theme. Sometimes I had many data points related to a theme and sometimes I had very few. Again, this was the process described by Smith et al. (2009).

Although this process of data analysis may appear linear, it is not. I believe that through my initial immersion in the data, I subconsciously began to identify and interpret themes. Having to pull data from the transcripts to support the themes I had identified became a critical step, as the mined data either confirmed or refuted these themes. I used not only the transcript for themes but also my notations and field notes. I began to look for overarching themes, or what Smith et al. (2009) referred to as super-ordinate themes. This search required me to rethink some of the themes that I had identified and to change

the names of a few, collapse some, and delete others. After the analysis, I came up with five super-ordinate themes.

I repeated this process with the additional 12 interview transcripts. When I had identified the super-ordinate themes for all of the interviews, I began to look for themes that cut across the data. This search required an iterative process of going between the data, my notes, and the themes. Through this process, I began to collapse and rename super-ordinate themes to arrive at the final set of themes; these were based upon my interpretation of the data and supported by the data.

### **Ethical Issues for Consideration in this Study**

Denzin and Lincoln (2005) argued that “All inquiry is moral and political,” (p. X) and other scholars have agreed (Brinkmann & Kvale, 2005; Knight, 2000). Qualitative research has been identified as a democratic approach to research (Brinkmann & Kvale, 2005) with study participants as co-creators of knowledge. However, this broad statement obscures the salient issues of subjectivity, power, and ethics. Given that empowerment is a theme that runs throughout this study, all aspects of this study should reflect it. In addition, as this is an interpretive phenomenological study, it is critical that my biases be made explicit.

Ethics should be of concern in any research project. Qualitative research involves an intimate relationship between researcher and participant that gives the appearance of a more ethical form of research. However, Brinkmann and Kvale (2005) contended the opposite: false relationships formed for the sole purpose of obtaining data can be “softer seductive forms of power through dialogue, empathy, and intimacy” (p. 162) resulting in

a “manipulated dialogue” (p. 164). Ethical issues in this study are more salient, given that the participants were already marginalized and the study theme is empowerment. For these reasons, it is essential for me to make explicit the issues related to ethics and power in this research process.

For this research study, I am most concerned with three things. The first area of concern revolves around my prior relationship to the participants. The second is the ability to apply the empowerment model through sharing power and control throughout the research process. Last, I have striven to maintain ethicality throughout the entire study and have particularly considered the ethical issues involved in providing a monetary gift to participants.

### **Researcher Biases Unmasked Using Reflexivity**

To monitor my biases, understand my personal growth, and understand my role as a co-creator of knowledge, I engaged in a reflexive process as described earlier. I used a research notebook that served as the repository of my data notes, field notes, and reflective notes. The first steps in this data log were to acknowledge my own biases and remain open to discovering biases I had not previously identified. Interpretive notes completed the data collection process. Alex and Hammarstrom (2008) contended that this process of reflexivity is an essential component of the analytical process and adds quality to study findings.

One component of reflexivity included referring back to my interpretive notes and recognizing that I was part of the research (Richards, 2006). As part of this reflexive process, I kept a data log that captured my thoughts, feelings, and reactions at each step

of this study including research, data collection and analysis, and reporting (Richards, 2006). This data log was important as a way to trace my decision points, decisions, and what I learned. This journey of reflexivity is about me as represented through my insights and critical analysis (Villaverde, 2008). The data notes included setting notes, which were the descriptions of contexts, and the interpretive notes, which were about my reflections. Context referred to the surrounding conditions, such as where the interviews were taking place. This included noting what else was happening during the interview, who was present, and describing the tone or tenor of the interview including such things as body language. These data were not captured on the audio tapes; however, I included them in my setting notes and referred to them as I conducted the analysis. As soon as possible after each interview, I detailed its contextual components. Through my data and reflexivity log, I continually tried to check my biases and perceptions during all phases of this research study, including design, implementation, data analysis, and description of the findings. I describe my reflections and interpretations of these reflections in next section below of this chapter.

In addition, I have been a tangential member of the community under study. As a technical-assistance advisor, I was present through the creation and dissolution of many of the family-run organizations in which my participants were involved. I, too, have personal experiences regarding family-run organizations operating under SOC demonstration grants. Bloom (1998) highlighted the necessity of continually examining the interpretation of events that one's own life history creates. Throughout the reflection process, I was guided by the words of Villaverde (2008): "The researcher needs to know

enough, yet not be locked in, and must be willing to unlearn for the sake of what is yet to be learned and done” (p. 196). This delicate balance requires vigilance and persistence on the part of the researcher. I shared my known biases earlier in this dissertation, the primary bias being that I believed that the family-run organizations were a vehicle for parent empowerment. This journey of reflexivity is about me and my insights about myself through critical analysis (Villaverde, 2008) as I am the one making the interpretation.

I had biases based upon my own relationships with the parents in this study; I had previous, and sometimes personal, relationships with many of them. The downside of having previous relationships was that they sometimes blurred our respective roles during the research, which at times resulted in the sharing of information more appropriate to a friend than a researcher (Paradis, 2000). I did find, at times, that I needed to monitor my interactions and keep in mind that these were not personal conversations. At times, this was very difficult. After conducting my first interview and reflecting in my data log, I ascertained that I needed to pay close attention to my interactions so that I honored previous relationships yet remained in my role as researcher. Although no participant voiced this sentiment, I think some of the participants might have felt a little awkward when I assumed a different, more formal role.

In Chapter II, I identified feminist theory as one of the two theoretical frameworks that have informed this study. My initial assumptions, going into this study, were that the participants would identify their roles as women, and that the status accorded to women would prove to be an important factor in how they were treated by professionals. After

my first interview, when I asked a prompting questioning about “factors influencing how you were treated,” there was no mention of being a female as part of the reason for being accorded little respect. I noted this in my log. After about the fourth interview, I realized that I needed to challenge my assumptions that participants were (a) aware of their roles as women and the roles of women in this world; and (b) aware that their roles as women could influence how other people treated them. I still believe that being a woman in a male-dominated society results in discrimination and oppression (Crary, 2001).

However, my assumption that the participants in this study may have felt the same thing was incorrect. Another unexpected finding for me was that is that these parents did not separate their roles in the family-organizations as separate from finding services for their children. The interviews about the family-run organizations were deeply entwined with the service-delivery system these parents were also navigating for their children.

Whereas I saw these things as different from each other, the parents/participants did not. Several times during interviews, I thought we were talking about the family-run organization only to find out that the participant was talking about the larger service system.

I also had a “reawakening.” When I worked closely with parents who had staffed family-run organizations I became used to their various lifestyles, including the busy family-resource centers and the lives of the parents. Often there were multiple people around, little quiet, and an ongoing stream of phone calls, children, and activity. During one of my interviews, I began to feel annoyed. I quickly made a mental note of this and pushed it aside. After much reflection, I realized that I had easily moved back into my

perceptions, as a member of the middle class and a childless woman, of how life should be. Not only was this an eye-opening revelation to me, as a result I realized that my position as an outsider was now even larger than I had previously understood.

Re-entering the world of privilege without an ongoing connection to those individuals who were not part of this world, I realized that I had begun to lose my grounding in the essence of their lives. I began to see how easy it is to slip out of understanding, and with this slip, begin to lose some of my compassion and empathy. Although the dominant cultural narratives did not take over, I could feel their influence creeping in on my thinking. It is as if one must constantly fight against these narratives by maintaining real, ongoing connections with the people who are denigrated by them. For example, during one interview in a crowded restaurant, I was straining to hear, worried that my tape recorder would not pick up the noise. I began to feel frustrated. After the interview, in reflecting on my feelings, I began to understand that I was focusing more on the outcome of the interview, the interview tape, than on the connection, the relationship, and the message; I realized that I was acting outside of the values I had set for myself. I had let my stated goals and the outcomes I was determined to reach take priority over the human connection and the story. These emotions were embarrassing to me, and demonstrated the ease by which those of us in the mainstream can lose our connections to those outside of it.

### **Prior Relationships with Study Participants**

My role with several of the research participants is ongoing; moreover, I had relationships with all of the participants prior to this study. For many of these parents, I

was merely their technical-assistance provider. For others, this relationship morphed into personal friendships that have endured long after the conclusions of their organizations' SOC grants. For the majority of the people I invited to participate in this study, my perception is that our relationships include a foundation of trust. I believe that my relationships with the participants enhanced the interview process by allowing the interviews to naturally flow into a conversational tone, which "privileges the relational" component (Bloom, 1998, p. 28).

It is important to note that I am not an insider. An insider is someone who shares the same lived experiences as the participants (McGinn, 2005), someone who has walked in their shoes, so to speak. But I have not. I have not raised a child with a mental health issue; I have no children. Therefore, I have no first-hand experience with suffering the stigma described in Chapter II. Although most of the participants were females, as am I, by virtue of socioeconomic status and education I occupy a higher positionality in the social stratum. I am a privileged "other." These distinctions are real, and they are important in that they influence not only my beliefs, perceptions, and actions, but also those of the participating parents. Being born White and middle class, and having an education, confer privilege (Liu, Pickett, & Ivey, 2007; McIntosh, 1995) that can become a barrier to the authentic relationships that form the core of qualitative research.

It is congruent with feminist theory to create non-hierarchical relationships with an emphasis on reducing the power disparities between researcher and participant that originate from their different positionalities (Bloom, 1998; Soni-Sinha, 2008). In addition, given that this study is on perceptions of empowerment, it is crucial that I attend



to power issues, particularly as the person who was asking the questions and writing up the results.

Rebalancing the power between the “expert” researcher and the participant is another challenge (O’Connor & O’Neill, 2004). Hoffman (2007) argued that issues of power and the shifts of power between researchers and study participants comprise yet another data source. Koro-Ljungberg, Busing, Williamson, & M’Cormack-Hale (2008) agreed and added that this attention to power and power shifts between researcher and participant assists the researcher in “better awareness of the nuances and situate meaning within the data and the researchers’ interpretations and reactions to the data” (p. 340). As Hoffman (2007) described the role of power in an open-ended interview process, “The interviewer has power in that she initiated the interview, framed the process in terms of the questions asked, and shaped how others understand the interviewee’s story” (p. 333). The interviewee also has power in that “she possesses the knowledge that the interviewer seeks and she can determined how much of, and how, this knowledge will be shared” (p. 333). However, the balance of power shifts during different phases of a study (Karnieli-Miller, Strier, & Pessach, 2009). Furthermore, given the centrality of the role power can play, these authors have argued that understanding the conceptual frame for power relations in research is imperative (Karnieli-Miller et al., 2009).

### **Payment for Participation**

As the researcher, I tried to be consciously aware that I am a privileged outsider; this is one reason I chose to pay participants for their time. Paying people for participating in research studies is common in both qualitative and quantitative research

(Head, 2002; Russell, Moralejo, & Burgess, 2000; Paradis, 2000), but research on this topic is sparse. Two primary reasons for use of monetary remuneration for participation are that it increases participation (Head, 2002; Slomka, McCurdy, Ratliff, Timpons, & Williams, 2007) and that it is a means of equalizing power between researcher and participant and showing respect that the participant's knowledge and time are valued (Morse, 2005; Russell, Moralejo, & Burgess, 2000). Morse (2005) further elaborated on the theme of respect by saying that "paying participants is an act of respect, acknowledging the essential nature of their contribution, their expertise and their wisdom as a critical component of our research" (p. 727). My beliefs coincide with Morse's: without the gifts of people's stories and time, I would have no study.

### **Form, Amount, and Timing of Payments**

Singer and Kulka (2002) reported that the federal Office of Management and Budget had approved financial incentives for participants in research. That amount, which is still between \$20 and \$30 per individual, is consistent with the payments given for SOC research studies (Brown, 2009). Payment for participation in this study was given in the form of a Visa card for exactly \$25.00. To mitigate the idea that participants had to answer all of the questions or did not have the right to end the interview at any point, I handed each participant her Visa card payment at the beginning of the interview. This assured that the payment was not contingent upon answers the parent gave or the amount of time the interview took.

Following the guidelines provided by Smith et al. (2009) regarding the steps to complete a phenomenological study, this chapter describes the implementation of an

interpretive, phenomenological study based upon a Heideggerian tradition. My interviews with eight parents about their experiences of staffing family-run organizations under SOC grants were both a challenge and a delight. The challenge came from the locations of the interviews and the amount of time and travel they required. The delight was in reconnecting with the parents and to hear them discuss their experiences, in their own words.

The social justice tradition espoused by several scholars including House (1991) and O'Connor and O'Neill (2004) allows for giving weight to the voice of these women who are marginalized through their lack of income, their use of public services, and who are further stigmatized by their children's mental health challenges. Although the federally funded SOC grants are given extensive national programmatic evaluations, experiences with and results of being family members operating such organizations for other families raising children with SED are not captured. Because their individual or collective voices are rarely heard speaking about their experiences operating a family-run organization under a SOC grant, they fall outside the scope of democratic participation (House & Howe, 1999; Stufflebeam, 2001) in SOC evaluation. This group of families lacked both voice and power for securing services for their children. Empowerment of families requires the sharing of power between service providers and service recipients (Cooper & Christie, 2005), yet little is known about the nature and perceptions of power-sharing by the families whose members receive services.

A phenomenological approach reveals the stories of these families. These stories include their experiences with their children's mental-health concerns, their experiences

with the public helping systems prior to, and including grant funded child mental health system, and the continued impact of these experiences on them and their families after the grants ended. This study attempts to honor the stories of women who are raising children who have mental health issues and have analyzed these stories for connections among the cultural, sociological, psychological, and political dimensions of their experiences (Brown, 2009).

## **CHAPTER IV**

### **ANALYSIS**

Issues surrounding children's mental health are fraught with stigma that results in inadequately funded and fragmented services, as well as the denigration of the mothers who are raising children who have mental health challenges. Under the current professional helping system, the outcomes for children and their families can be dreadful. The SOC model with its component of family-run organizations is an alternative method of delivering needed services and supports. Because services supported through public funds have income eligibility guidelines, most of the mothers I interviewed were on the lower end of the income scale when they were accessing services for their children.

I had the privilege of working with many mothers who were not only raising children who had mental health challenges but who were also experiencing the phenomena of staffing a family-run organization under the SOC model. Before these mothers found their way to working at the family-run organization, they were often members of a group that one mother described as: “. . . families who had been sort of beat down by the system and sort of blamed for what was going on in their children's lives.” After a few years of working in a family-run organization, sometimes as few as three years, these same mothers had become advocates for their own families and for many other families. My interest in social justice and gender studies, were the factors that led me to explore this topic for my dissertation.

This study examines parents' experiences with the phenomenon of staffing family-run organizations over two distinct periods: prior to and during their involvement with a family-run organization. Based upon qualitative research with interviews as the data source, in this chapter I provide an analysis of the data that I gathered via interviews with the eight mothers who had direct experience with staffing family-run organizations under SOC. The data were identified using the methods described in Chapter III. What follows is a brief review of the analysis framework that I used based upon the work of Smith et al. (2009). After I became deeply immersed in the data through listening, reading, and transcribing, I first identified themes in each individual interview and then identified the themes that cut across all of the interviews. Super-ordinate themes appeared, and in a few cases, sub-themes appeared to support the super-ordinate themes.

I identified four super-ordinate themes: (a) purpose, which describes what was driving the mothers at that time; (b) power, which comprises the three sub-themes of knowledge, identity and control; (c) support, which refers to the amount and types of support the parents felt they had; and (d) opportunity, which refers to the level of participation parents had at both a micro level (about decisions that impacted their families) and a macro level, (the socio-political level). Although some of the quotations that follow are embedded in other themes, there were many about relationships with professionals that I felt the subject warranted its own section and is addressed in Chapter IV.

The data are represented as a comparison of themes prior to and during staffing of a family-run organization under SOC. This method of comparing and contrasting the

findings represents a polarity of responses and highlights the transformative power of staffing a family-run organization under the SOC model. The next section begins with a chart (Table 2) that depicts the super-ordinate and sub-themes at each period (i.e., prior to and during staffing). The quotes that describe the themes prior to staffing a family-run organization are followed by the quotes that describe the themes during the staffing of a family-run organization. Organizing the quotes in this way more clearly illustrates the differences among the narratives.

**Table 2. Analysis Themes**

<b>Super-ordinate and Sub-themes</b>	
<b>Prior to SOC Grant Funding</b>	<b>During SOC Grant Funding</b>
<b>Super-ordinate Theme 1</b> <b>Purpose</b> <i>Internal—Support for Their Child</i>	<b>Super-ordinate Theme 1</b> <b>Purpose</b> <i>External—Supporting Other Parents</i>
<b>Super-ordinate Theme 2</b> <b>Social Support</b> <i>Lack of Social Support</i>	<b>Super-ordinate Theme 2</b> <b>Social Support</b> <i>Supported by People Who Understand</i>
<b>Super-ordinate Theme 3</b> <b>Power</b> <i>Sense of Powerlessness</i>	<b>Super-ordinate Theme 3</b> <b>Power</b> <i>Sense of Empowerment</i>
<b>Sub-Theme – Knowledge</b> <i>Lack of Knowledge Regarding Services</i>	<b>Sub-Theme – Knowledge</b> <i>Knowledgeable- Teaching Others</i>
<b>Sub-Theme – Identity</b> <i>Parent is the Problem</i>	<b>Sub-Theme – Identity</b> <i>Parent is an Advocate</i>

**Table 2. (Cont.)**

<b>Super-ordinate and Sub-themes</b>	
<b>PRIOR TO SOC GRANT FUNDING</b>	<b>DURING SOC GRANT FUNDING</b>
<i>Sub-Theme – Control</i> <i>Inability to Control Services</i>	<i>Sub-Theme – Control</i> <i>Making Decisions and Negotiating</i>
<b>Super-ordinate Theme 4</b> <b>Opportunity</b>	<b>Super-ordinate Theme 4</b> <b>Opportunity</b>
<i>Sub-Theme – Participation</i> <i>Excluded from Decisions for Child</i>	<i>Sub-Theme – Participation</i> <i>Active in Decision Making</i>

### **Analysis of the Interview Data that Produced Themes**

As I analyzed the data, I had to hear the words and the emotions behind them, and listen for their meanings. My goal was to combine the experiences as expressed by the parents into a coherent narrative that is representative of their experiences with the phenomenon of staffing a family-run organization. This analysis section begins the same way most parents began their stories: with a description of how and when they knew that their child was developing atypically. In the next section I illustrate the super-ordinate and sub-themes, using quotes from the parents in their own voices both prior to and during their staffing of a family-run organization. The section after that contains a discussion of parents' relationships with professionals and the new opportunities parents had to participate in policy-making bodies.

The organization of the quotes follows the sections as I have outlined. The first quotes describe the early diagnoses of the participants' children; the next quotes are



related to the super-ordinate and sub-themes that capture the participants' experiences prior to their involvement with the family-run organization. The next set of quotes is the comparison quotes, in the same format, that describe participants' experiences during their involvement with the family-run organization.

The quotations included in this study, which are verbatim, were taken from interview transcripts and from notes that I wrote during the interview process. I changed the genders of the children and the location of the interviews. No names of children, parents, providers, or agencies are provided. All of the edits I performed on the quotes were in the interest of protecting the confidentiality of the participants. These minor changes do not affect the content or the quality of the data. It should be noted that in some of the quotes, parents were speaking about their own lives and sometimes they were referring to their work with other parents.

### **Early Diagnosis of Children's Mental Illness**

By the time the SOC entered their lives, these parents had had many years of experience seeking services and testing strategies to obtain support for their children. As many of the quotes reveal, these parents were determined and persistent in trying to locate services for their children. The parents I interviewed went to great lengths, and showed little regard for their personal lives, in their efforts to support their children. The parents who participated in this study often started their stories at the point of their children's early behavior and diagnosis. Most of the parents knew their children were developing differently than other children at a very early age but almost none of them suspected that a mental health challenge was the cause. Many of the children had a

mental health diagnosis prior to elementary school and several children were receiving medication by the time they entered elementary school. As one parent related:

She [the pediatrician] finally gave [my child] an early diagnosis of Attention Hyperactivity Disorder and prescribed Ritalin for the first time, and this is about age four... We noticed that the Ritalin was not doing it. She was getting progressively worse... And so, the pediatrician finally referred us to a therapist... Prior to turning five and starting kindergarten, uh, she got a diagnosis of bipolar disorder, early-onset bipolar disorder.

Another parent shared that “She [the pediatrician] started her [the child] on ADHD medicine at age 4 but then she took her off of it before she started school.”

Another mother added this about her child. “She got uh, diagnosed with, um, ADHD at the age of 4. And then she got diagnoses of ODD and PTSD when she was 9 years old.”

### **Prior to Experiencing the Phenomenon of Staffing Family-Run Organizations**

**Super-ordinate Theme 1: Purpose.** For all of the parents interviewed, their concern for their children’s well-being was their driving purpose at this time in their lives. Every parent echoed this theme. The parents describe being frightened and shared their feelings of desperation for their children. The stories they shared of their experiences prior to SOC were poignant, powerful, and, at times, heartbreaking. This part of the interview often took the longest; when parents cried during the interviews, it was at this point in their stories.

Often, I could hear their frustration and feel their sorrow, still present so many years later. Many parents had been seeking services for their children for years with little luck and a growing sense of fear. All of the mothers I interviewed represented what Jane Knitzer (2005) referred to as the resiliency, commitment, and tenacity of parents, yet

these attributes were overshadowed by their experiences with the professional helping system. The quotes immediately following, taken from my interviews with the participants, capture the worry and fear for their children's safety that drove these parents at this time in their lives. One mother shared, "I knew that if I didn't do something, he wouldn't live. He wouldn't make it—he would either be dead or in he would be in jail." She then described this time in her life: "It was scary . . . lonely." Another mother recounted about her daughter: "And she was settin' fires, smokin', cuttin' herself, playin' with knives. I had to lock up all the knives, all the medicine stuff." Another mother shared:

As my son got older, he would often leave the house in the middle of the night. . . . It's very frightening because every time I heard something on the news about a body found, or something, I held my breath because I did not know [if this was my child].

The quest for services and the realization that nothing was helping her son added to this same mother's fear and worry. "Every time I'd do something, I would think that this would be the something, that this would be the something, that maybe this would be the something [that worked]. And every time it wasn't, it just made you more afraid."

This mother continues:

It was, I couldn't understand why my bright, intelligent child fought all the time, got kicked out of school all the time, um, was flying it sometimes and completely failing it others, why, things that he had never experienced in the home she was out doing- you name it.

**Super-ordinate Theme 2: Social support.** This super-ordinate theme refers to relationships the participants had with other people in their lives and in their communities that incorporated their sense of social support. Many of the parents felt alone, with little support; they were navigating this journey on their own. Of the parents who did have support, the most frequently mentioned type of support was from their church families and sometimes work colleagues or old friends. It is important to acknowledge that the few parents, who did mention some support from doctors, their church family, or friends, also recognized that no one in their support system had a similar experience of raising a child who had a mental health challenge. When most of the parents talked about their social support, there was hesitancy in their voices or often a pause, as if they had to think this through to identify their support system. Only one of the parents who I interviewed could readily name a strong, robust social-support system. The next set of quotes reflects the parents' feelings about social support.

As one parent said: "No, to be honest [no support]. No, umm, to be honest with you, the greatest level of support and help that I felt I received through day one, the day my son was diagnosed, was his doctor." This parent went on to talk about how she felt about having support:

So the support, the support, family support, my mom was always there. She didn't quite understand it, but she was always there. But, I think this road was traveled mostly alone. And that was okay. You know what I'm saying? That was okay.

Another parent share that she, too, had no support. The parent shared that she had, "Nobody [for support]. I had absolutely nobody before I went into SOC."

Still another parent reported, with hesitancy, “I had a couple of family members . . . and a couple from church, but that was about it. I mean, you know, my husband . . .”

Yet another mother shared that she had some general support, albeit from people who did not understand her circumstances: “But they [a few extended family members] were very supportive, and I know if I needed anything, you know, they’d be there, but they didn’t understand mental health.”

Last, another mother said: “Well, his doctor helped me some.”

**Super-ordinate Theme 3: Power.** The parents’ care and concern for their children’s deteriorating behavior was fueled by their perception of their own powerlessness to locate support and services that worked for their children and for their family unit. Parents tried everything they knew to do to help their children, but they had no idea what services were available to their children or where to turn for assistance. Parents’ lack of knowledge about services, their lack of control once they found services, and the negative messages they received about who they were as parents, all combined augment their sense of powerlessness.

**Sub-theme: Knowledge.** Without experience with, or knowledge about, child mental health challenges, these parents had no idea what to do or even whom to call. This lack of knowledge about services resulted in feelings of helplessness. However, at the same time, the actions of the parents also demonstrated their tenacity and resolve to do something, anything that would assist their child, as the next set of quotes illustrates.

One mother shared this lack of knowledge when she said, “I had no idea what to do, no idea. I had to do the entire work to find the resources to support him.” This was supported by another mother who claimed, “So, I was beatin’ the bushes and doing all of that anyway, but I was just not aware of everything that was out there for [my daughter].” Yet another mother talked about her journey to find services: “Where I just called people all day long saying, ‘This is what’s going on, can you help me?’ Calling everyone, telling my story every time and saying, ‘Can you help me?’” This mother said, “I spent days on the phone call [for services] and hearing, ‘Oh, we don’t do that, I would let my child do that.’” This same mother explained that she was in a

. . . Relentless search for services—traditional things didn’t work; Finally, I hung out with the police department and I would go to the Juvenile Court Office regularly and say, ‘What will it take? What does it take [to get services for my child]?’

The quote below, from another mother, sums up the themes I heard from all of the parents I interviewed: “[I was] completely confused. I had no, no clue what to do.” This theme was led to parents’ sense of powerlessness and loss of control. Even though parents were trying everything they knew how to do, they still could not find what they needed.

***Sub-theme: Control.*** The themes of power and control are related because it often takes knowledge and power to exert control. Recognition of the relatedness of these two themes is reflected in the quotes below. When parents found services for their children, even though they had persistently sought such services, their sense of powerlessness often increased because they felt they had lost control over their children’s

welfare through their involvement with the professional helping system. Although, some parents spoke highly of some practitioners who had treated them with care and compassion, their stories express their sense of having little control over services and providers. Often they feared that their children could be taken from them.

I didn't ever feel like I was out of control until the system got involved and started giving me choices, none of which I liked. And I felt completely out of control with that. I felt like once they got in my life, they would never get out, and I felt threatened. I felt afraid that I would lose custody that, um, they would find me neglectful.

This same mother shared that:

I don't think people realize how many people get involved in your life when your child has special needs. And they just dump all these people in your life, and they come in your life with the attitude that 'We're the professionals, and we are going to tell you how to raise your family. We're gonna tell you what you should and shouldn't do, what's right and wrong.'

According to another mother who shared, "We just had a lot of people in our house and nobody really kinda told us what was going on." This sense of loss of control was shared by a mother who sought professional services for her four-year-old daughter.

I was told that she [my daughter] probably wouldn't appropriately fit within the regular school system. Um, now at that time, I had no idea what that meant. Um, so it was decided at a meeting [which I wasn't at] that because they [providers] didn't have an appropriate school for her within the county that she would go to a residential treatment facility . . . and I remember realizing that I didn't have an option.

Another mother shared that she had:

That the person-centered plan, I didn't really understand them. So, they [the professionals] could do their little professional talk and talk around things and I didn't quite understand it so they [professionals] thought they could just talk through it and I would take them at what they said.

Another mother shared that she had:

Absolutely none [control over resources.] [Professionals thought] parents are wrong, and I [the professional] know what is better for this kid than the parent does. You did something wrong, you're not a good parent; therefore you can't be part of the solution.

This same mother eventually resorted to a desperate measure and having her child arrested so she could get court- appointed services, knowing this was a gamble and she could lose all control, she did it with the hopes that her child would finally receive needed services. She shares her feelings about this decision, "It was really, really hard. It was hard to have your child arrested, 'cause the scary piece about if you get involved, uh, with the court system, it could spin out of your control."

Another mother explained the discouragement that sometimes results from the lack of services:

Because a lot of times they [providers] just completely gave up. And the same with the parents, like [they would say], 'Put them [the children] in the foster care, what else can we do?' You know, that's what they're [providers] are wanting.

The foster care option, which includes group homes, is the option of temporarily placing your child in the care of others who have been sanctioned by the state; ostensibly,



these people know how to better care for one's child and have access to more resources. The option of placing the child out of the house into state provided care was mentioned several times in the interviews with parents. The foster care system was discussed sometimes concerning their own children as well as children in other families. The option was not always viable option, however. It was never an easy decision, but one usually made in the hopes that it would help their children. One mother shared that, "I had exhausted every other resource I could possibly think of, so I placed him out of home for a while."

Participants said that some practitioners in foster care and group home settings did not have the skills or abilities to work effectively with children. One mother shared: "I got a phone call at about 5 o'clock in the morning [from the group home] saying, 'Your daughter has terrorized every child here. I need you to come and get your daughter.'"

***Sub-theme: Identity.*** Parents' sense of identity suffered from their lack of knowledge, inability to find or control services for their children, and the subsequent blame heaped upon them for their children's illnesses and ensuing behaviors. Blame came from many sources, including the professional helping systems, their own families and friends, and themselves. The number of references to blame was by far the largest category of quotes in this study. This number is indicative of the time parents spent feeling blamed and how deeply they identified with that blame. Mothers relayed the following quotes about blame.

One mother shared that "People [professionals] in mental health were always telling the parents what they were doing wrong." Another mother reported that she knew

there were challenges in her life, but the providers took it to the next level: “So it’s like the system lets you know that you’re dysfunctional.”

Another mother shared that she was told by providers:

‘You must not be making her, you know, obey at home. You must not be structuring things at home.’ And they [providers] were saying these things to me at our meetings, and I was really feeling horrible about that. I’m thinking, ‘What am I doing?’ [. . .]

I knew that there was something going on, so whether it was my parenting or not, I knew that it had to be something, and for a while I accepted the fact that, ‘Oh, maybe I need to do something different.’ So then, I blamed myself. ‘Oh, I wonder what I’m doing wrong.’

According to another mother:

The child’s behavior is blamed on primarily the mother but definitely poor parenting, poor boundary setting around the kids, not setting them as right, that’s why contracts with your kids is so popular. Um, but that, none of that was working for me.

Parents felt pressure to prove they were sane and stable, and not the cause of their children’s problems. One of the mothers recounted:

Um, you couldn’t be too emotional to do that. Couldn’t break down, couldn’t be crying, and or they [providers] just saw you as a weak, vulnerable bad parent who had already screwed up their kid. So, you know, it was rough.

In addition to feeling blamed by service providers, parents often felt blame from their own families and friends. One mother said, “My family pretty much blamed me.”

Later in the interview, she added:

And it was really easy on any given day for me to hear what countless other parents heard, ‘If you beat her more, if you beat her less, if you gave her less, if you gave her more, if you let me have her for a day, if you let me keep her for a week, I could straighten her out’—all that easy fix stuff to what was really very complicated.

Another mother described a similar experience:

Um, I think that they felt that I should have had more control over [my daughter] and made her listen more, and made her participate more. Um, as she got older, you know like 15–16 she was a lot bigger than me. I couldn’t force her to take the meds [medications] anymore. And they thought that I should have been able to somehow do it. They thought I was, um, too lenient, which in some things I think I was because I felt very, very guilty.

In her second interview, one mother said:

So much of who we are is defined by how well your child is doing. You brought them here, you are their navigator and it is your responsibility to beat back the bushes and give them a change. For our children it is like trying to beat back the jungle.

Parents felt devaluated by the professional helping system in other ways as well. They often felt that practitioners thought less of them for their lack of formal education, even though some had college credits and degrees and others had started their own businesses. Many felt they were viewed as “just a parent.” As one mother said: “[Providers] talk to you as a peon—[they] don’t treat you as equals.”

Other parents realized that this devaluation was due to providers’ perceptions of their lack of education and socioeconomic status. The following quotes from three different parents illustrate this concept. The first mother recounted that “. . . education-wise, they [providers] felt that parents that did not have degrees [that they] didn’t have a

clue, they just had the child. This mother went on to say, “I was angry, I was angry because of the things that were coming from the people that I am asking for help, mouths.” The second mother confirmed this experience: “If you don’t have an education behind you, no dress clothes, they [providers] don’t take you seriously.” The third mother said:

A person like me, a parent with a child with extreme mental health challenges, you could see the total difference of their body language and the way they spoke to you at the table. You weren’t as valued as [if you had] the doctorate degree...

A fourth mother added: “At certain times, um, organizations, front-line workers, would try to intimidate you because of your financial status or educational background.”

The system policies that dictates the income levels of parents who access public mental health services for their children also prevents parents from developing careers and acquiring assets. The state of enforced deprivation that results negatively impacts parents’ senses of identity and self-worth.

By having a child with special needs, it limits your ability to move up any kind of system because of the required care that these children need. The laws are such, even if you had private insurance, the mental-health benefits run out so fast, you have to do something differently to get the care for your children. I literally had to turn raises down, as my career has gone on in the system... had to turn raises down because if we made a dollar more, I would lose her Medicaid, and her Medicaid I can’t lose. She has got to have her medications in order to stay stable and to get treatment, so we had to keep Medicaid. I had to hold myself back in my career to get my child’s care and we have never had a home because we couldn’t make enough money to build a home, we have had to rent. The system was set up where there was no way for us to move. There is no insurance company that is going to cover her care, not with the amount of care she has to have.

For parents who were trying everything as they relentlessly sought help for the children they loved, this blame was tremendously hurtful. These parents began to identify with the negative messages reflected at them. This theme, which often surfaced repeatedly, resonated in every interview. As one mother related: “I felt very guilty. I should have done more . . .” This mother elaborated, my daughter was blamed, I was blamed, you know? We just couldn’t fix it, you know, with what they were doing.” Later in the interview, this mother returned to the theme of guilt:

I was carrying so much guilt that I was just kind of, I was stuck. I, I was just stuck. No confidence at all. Especially when it came to, you know, working with the schools and the mental health with my daughter, and everything. And, that just fed on over into my personal, you know, me, because I felt so inadequate as a parent, and being able to help my daughter do well. That just tore me down, too.

Her summation about this point in her life is, “[It was] Just hell. [I felt], Um, sad. And, [I felt] a lot of guilt, and helpless.” Still another mother recounts of her experience with blame, “The first person you blame is yourself. The first person other people blame are yourselves. And the first person the professionals blame usually are you. So it gets compounded.”

**Super-ordinate Theme 4: Opportunity.** For many of the reasons shared above, parents felt they had no choice but to accept the services provided to them. Initially, parents acquiesced as services were decided upon and provided, even though they were not included in decision-making processes. Prior to involvement with the family-run organizations, parents did not feel they could challenge the system or the services in a

systematic way. As parents tell their stories, this acceptance is reflected in the quotes below. One mother recounted the story of her how her daughter was medicated.

She was at the point where she was just medicated into submission. There wasn't—relieving any of the underlying symptoms. It was just sedating her enough so she wasn't gonna blow up. I thought, you know, they got PhDs and doctorates, and I thought it wasn't really something I understood.

Another mother described a similar thought:

And they [parents] felt like they didn't have no choice in the matter, that they had to do what they [professionals] said to do, or else the kid wouldn't get to services or the kid may be taken out of the home or you know . . .

Still another mother related that “There was a lot of negativity [from providers], especially if you didn't go with the flow.” As another mother recounted “. . . families who felt like if they did speak up, that anybody would be listening; they didn't feel validated.” Still another mother said: “You know, they [professionals] were doing those [service plans], it was all professionals sitting at the table at one point, you know. And the parents wasn't being involved.” Later in her interview, when this mother was sharing how she felt regarding the level of control, she said she had “absolutely none.”

If we were to stop here with the story of these parents, as they attempted to raise their children prior to their experiences with family-run organizations, we might feel their pain and sorrow over being burdened by implied blame for their children's problems. We would probably recognize their narratives as stories of people who are alone, fighting a system, and being beaten down in the process. However, the SOC grants did come into being, based on a different philosophy from the traditional service system, and the

parents who experienced the phenomenon of working in family-run organizations were forever changed. In the next section, I illustrate the super-ordinate and sub-ordinate themes with parents' statements about their experiences during and after their involvement with family-run organizations under SOC demonstration grants.

### **After Experiencing the Phenomenon of Staffing SOC Family-Run Organizations**

The transformation of families who staffed family-run organizations under SOC grants was significant. These grants broke new ground by including the expectation that parents of children receiving mental health services would become partners with professionals, with the goal of sharing power and gaining control not only over services to their own children, but also over the community resources provided for all children with similar needs. The SOC grants provided funds to provide training to parents in order to educate them about their rights within the professional helping systems, on effective advocacy and negotiation skills, and on common mental health challenges in children.

The language used in the quotes below reflects this transformation. They include more words of hope, pride, and excitement. During these portions of their interviews, parents' body language became more animated; they laughed more; and their voices became just a little louder. I could feel and hear their confidence.

**Super-ordinate Theme 1: Purpose.** One significant change described by parents was around their sense of purpose. As they become involved with family-run organizations, parents seemed to find their calling, a role in life that involved something more than just finding care for their children. Prior to SOC, their purpose had been to

find support and help for their children: not surprisingly, many parents expressed anxiety during the interviews when they recalled this time in their lives. But during their involvement with family-run organizations, their focus shifted from the exclusive, personal goal of finding services for their children to a wider goal of helping other parents who were raising children with mental health challenges. Having weathered their own interactions with professional helping systems, the parents I interviewed expressed a desire to prevent others from going through the same experience. The quotes below highlight these changes in how parents describe the additional purpose of their lives. As one mother recalls:

I was out of [a] job because of [my child's] needs and I went to the [parent] support group and within six months, they hired me to run the support group... And, then it became a purpose, I think. At that point, as I got into it, it wasn't just a job but to make a difference in other families' lives.

Another mother shared her feelings as to why she wanted to help other families. "It was just personal for me, very personal. But I know what it's like to be in their shoes, you know, I've been there at one point or another in some way, shape, form, or fashion."

Another mother recalled:

I was a single mom. And that was a real low time. And getting involved in this work gave me something to do to take all that hurt and anger from my child placed out of the home, and wanting to make it right. And then realizing that other parents were in the same place, and that maybe I could do something that would make it better for them, too.



Still another mother shared:

I enjoyed the fact that I was able to help somebody else through what I was dealin' with my own child. . . I was just so into it, I mean, I was just right there. I was head first, I mean, you know, wantin' to learn everything I could and get—be as involved as possible because, you know, the more I was doin', the more I learned, the better I could help [my child], and help other families.

One mother shared her experience providing support to another parent:

I mean, well she's going to school at night to be a lawyer. I mean the woman is bright but still she couldn't navigate the mental health system. She needed just somebody there beside her. I think most of it, what I did was just being beside them, you know?

**Super-ordinate Theme 2: Social support.** Prior to their participation in a family-run organization, parents shared that they had felt an overwhelming sense of loneliness. They had perceived little support and had known few others who understood what they were going through. However, through their experience with family-run organizations, parents no longer felt alone and isolated but instead found a strong sense of community.

One mother shared: "I would call them [other parents] on how to handle situations and mainly [they] let you know that you were not the only person who was going through what you were going through." Later in this interview, the same mother talked about other parents at the family-run organization she had staffed:

We [parents] would come together and have our little monthly meetings; we had meetings twice a month. All the parents would come together and meet here, and talk and about the different things we wanted to see done

here at the center. You know parents, we'd make a menu and different parents would bring in. Once somebody would bring a dish of this and somebody else would bring a dish of that and we would have enough to have our little meetings and be able share with the kids while we doing it.

Another mother talked about her support system: "[I] was able to make the network and connections through the networking piece of getting to know people." Another parent spoke of the support she received after SOC came into her life, and continues to receive:

Oh, it has gotten 100% better. I have a team around [my child], and we still have a team around my child after SOC. People don't get paid on that team, they have built, we built this team and people cared. [Before SOC] I didn't have anybody to [help], and now, I have a whole huge network of people I can call on to help.

Another parent spoke to the support she experienced through being with other parents who understood what she was experiencing with her child.

Well, first of all, it was the relationships [with other parents] that was involved and gettin' their perspectives. You know, and it gave us somebody to be with that knew what we were going through every day, ourselves as parents. So that was number one for me, you know, and it gave me a wider support group, you know, well-rounded support group.

Still another parent shared that, "We were helping families develop relationships where at first they did not have anyone to talk to."

**Super-ordinate Theme 3: Power.** The super-ordinate theme of power includes the three sub-themes of knowledge, control, and identity. As the data show, parents changed significantly in their perceptions of all three of these topics. It is almost as if this portion of their collective story is a different one about different parents. Their voices

expressed their awareness of this change within themselves: they began to speak with real confidence. The terminology around SOC, public laws, mental health, and medical terminology flowed with ease during these sections of their interviews: they spoke with an expert voice. These quotes describe the personal transformations that appeared to happen in tandem with parents' social transformation.

***Sub-theme 1: Knowledge.*** The parent training funded by SOC funds taught the mothers about their rights, how service systems operated, and help them to develop advocacy skills to navigate professional helping systems. Parents were hungry for knowledge, as the following quotes illustrate. One mother shared that she “really enjoyed learning. I felt like I was learning, like I had learned more in that five years than I had probably for 15 or 20. I felt like I grew more during that time.” This mother continued, “I really [had to] know the system whether it’s the mental health, juvenile justice, especially the school system. I mean I really had to study a lot and ask a lot of questions.” Another parent could not get enough of the trainings provided. She went to every training available; often she went multiple times to the same training.

I think I went to all of them [trainings], as much as possible. Some were right here in town, I never missed them. Sometime I went to the same thing, wherever I heard it was, I would go—I said ‘Well, maybe I missed something the last time they [inaudible] this year, I’m going again maybe I’ll pick up something different.’ And then, when we traveled away, it was the same. I would get to go as much as I could.

Some parents' self-esteem rose as a result of their new education. “As I began to get trained, that training made a huge difference, first for me to understand that I had not done anything to cause [my child's] illness.” Another mother said, with great pride in her

voice. “Girl, they [providers] hate to see you coming [once I had knowledge], they would start getting their p’s and q’s together, it made me feel powerful.” Another parent shared that, “Professionals change [towards you] when you get knowledge.” Later in the same interview this mother shared that:

And once I got in as a parent advocate, I was better able get further with [my son’s] stuff as well. Once I got more tools put in my hand, and learned the systems and his rights, and learned what should he could and could not have, you know, as a child that was disabled, you know—I was like, ‘Oh, wow!’

***Sub-theme 2: Control.*** Feeling knowledgeable, parents began taking control of the services offered for their children and no longer took the word of the professional as gospel. Embedded in the theme of control is the life-changing nature of this phenomenon. One mother shared:

Really, it changed my family’s life. I don’t think it would have changed [prior to the SOC]. I mean ’cause, we were heading down that same road for a long time, and I think by the time [my child] was at that last hospitalization, I had enough confidence to listen to her. And even though the doctors didn’t agree, they did help me step down her meds so that it was safe, and we could call them again, if we needed. So, they did listen. I don’t think if I hadn’t that little bit of confidence, they would have.

One mother, speaking as a parent advocate, shared her excitement as she watched other families take control:

I went to an IEP [Individualized Education Program] meeting and I spoke up and said this is what my child needed and they listened to me and they incorporated into my plan and then I went to my probation meeting. And then they were able to see that my child was improving in school and he was taken off probation. To see the difference, and to think, ‘Wow.’

Another parent related, “If I didn’t have the background [provided through SOC trainings], I wouldn’t have stood up [for what I wanted].” Still, another mother reported that this feeling of control has carried over into her personal life, in other situations, including her experiences with other health-care experiences:

So, yeah I felt comfortable speaking my mind even with my mom when she was in the hospital and the nursing home. I had a confidence that I wouldn’t have had years ago. I mean when I told them something I expected them—you know, ’cause I had power of attorney. Its like ‘You don’t change her meds without telling me,’ and that was it you know? Before I would be very timid. It would be very meek and I would have forgiven them whatever they did.

This parent also added: “And as I learned more about those documents are, what they’re supposed to be, what the language was, you know, I could, um, I could as the questions.” This mother continues, “She [her daughter] did better when I took her out of formal services...” This parent also stated: “They [the providers] weren’t gods anymore. I don’t know how else to put it. It wasn’t that I ignored what they said. I’d listen to what they’d say, but I also realized that they didn’t know everything.”

One mother succinctly stated, “[I was] never comfortable speaking out—[now I am] no longer comfortable being a doormat.” Still another mother described how she stood up to the providers to advocate for what she wanted:

They didn’t wanna bring her back into mainstream classroom, I said I don’t care what y’all want. You know, this is where she’s at. She’s able to come back here. So I set up the meetin’ with the case manager, with the principal at an[alternative school], with the principal at [a traditional school]—brought her back to mainstream classroom, took her off all her meds, cold turkey. So . . . and she was the better for bein’ off all her meds.

Another mother said: “It wasn’t that the system was going to raise our kids, but we had a responsibility and a right to be part of [ . . . ] and to make choices on how we wanted our families served.”

***Sub-theme 3: Identity.*** Armed with new senses of purpose, new knowledge, and a stronger sense of control, parents’ sense of self-worth increased. Parents also began to see themselves as valuable people. They now began to feel, too, that some providers saw them as valuable. Parents now thought of themselves as people with skills and recognized their own worth through their own eyes. Now, these parents were seen as the “experts” by the new parents they recruited.

At this point in their stories, participants frequently gave their role and title as “parent advocate” and for many of them; this was their job title if they were formally employed by the family-run organization. As one mother said: “I felt confident with my skills. And with who I was.” Another parent shared that she “helped the parent understand the process and the family said, ‘If you hadn’t been there, I wouldn’t have understood.’”

Another parent related that:

Um, the work was wonderful. Working with the families, which was always rewarding for me, a parent advocate . . . [I was] proudest working with families. I just a call from one of the parents that I worked with for probably three years, no four years. Um, her son’s doing great.

Another parent spoke with great pride of her transition to a provider of training services:

It [doing training for families and professionals] felt wonderful, it was really good. At one point, I'd done three trainings before it was all said and done, I did three trainings by myself. I still felt like I was just a parent, but a parent with a lot more tools in my hand that could act on a professional level.

As reported in a previous section, parents often felt devalued and disenfranchised by providers. That began to change, however, as the parents gained knowledge and confidence and began to see themselves as valuable and worthy. According to one mother: "But once they [providers] found out that I was a parent advocate there with somebody else's family besides my own, they still didn't like it, but they listened and was more open to me being there." This mother later described her experience as she conducted training for providers:

I mean I was very; I'm not very good at speaking' in a crowd of people. I'm very boisterous, I mean I could sit and talk to you one-on-one every day, or people that I'm comfortable with, I can sit and talk to all day, but training, I was a little bit skeptical 'cause I thought 'Well I'm just a parent, you know, and it don't mean much, or whatever., But people [other parents and providers] would come up to me and tell me, 'you know, what you had to say, what you taught, your part of the training meant more to us than anybody.'

Another mother recalled with pride how she felt she felt that she was positively perceived by providers: "And the thing was 'Oh she's a force to reckoned with, you'd better have your stuff in order because she'll call you out.'"

**Super-ordinate Theme 4: Opportunity.** This new sense of purpose, combined with the knowledge and recognition that they, as parents, had value and worth, and also coupled with a sense of community, moved parents to seize the opportunities afforded by the grant language on every possible level. As previously stated parents assumed

advocacy roles, trained other parents, and increased their voice and participation in policy-making. Some began trying to transform the system by attempting to help professionals change their attitudes and behaviors toward parents.

Parents used their roles on policy-making committees to bring about systemic reform. Although they were not always welcome at these tables, they stayed put and continued to advocate for improved services to families. Parents saw this activism as part of their purpose. Not only did parents confront providers with feedback about the services they were receiving, they also tried to change the systems that were serving them, their children, and all children with mental health challenges.

An important component of parents' motivation for this type of involvement was contained in the SOC grants, which mandated partnerships between professionals and families. The SOC grants also mandated the creation of state and local community collaboratives (i.e., local and state advisory boards that included representatives of child-serving agencies and parents who were raising children with mental health challenges); as a result, policy-making bodies were formed that were required to include parental representation. Initially, parents may not have felt comfortable participating in these groups, but as their senses of knowledge, self, and purpose grew, so did their level of participation. The first set of quotes relates to parents' experiences serving on policy-making bodies and the second set relates to parents' efforts to change professional-care systems by transforming their professional practices. In the next group of quotes, parents describe how they took opportunities to try to change professional practices with which they interacted.



Little training was provided to help parents know how to participate and to work with policy-makers and professionals to create change but they persevered and learned on their own. As one parent described the situation, “The money from the System of Care grants forced those people [professionals] to actually even have those people [parents] at the table.” Another parent said:

But I tell you what, the first I don’t know how many months I went to those meetings [policy-making meetings] and it felt like a foreign language. I remember, I don’t know how many months—maybe six or seven months—I just—and lotta times I wouldn’t come. It just felt like—I had no idea what they were talking about. And uh, and they were probably okay with me not knowing what they were talking about ’cause I had no input.

One parent recalled her experiences as part of a policy-making board and finally being accepted, more or less, by providers:

I think it was a really big battle in the beginning to get people [providers] to accept us at the table, I think looking back over the years...I would say there were a couple of shifts that I seen of acceptance and finally accepting us at the table and then hearing some of the initiatives that we would like see changed within the community and how they served families. I do think that we became recognized—sort of, as a peer, at the table.

Another mother said:

Most of the committees, I was just the token parent. I mean it doesn’t mean people weren’t nice or respectful . . . I was a parent—you know, through the System of Care you have to have parents on committees that have children with mental health concerns and I was one of them. And I think they saw me as fairly . . . And I think I appeared to them higher-functioning.

Another mother was on two policy-making bodies in her community. “Oh, yes I was on CFACT committee and I was on Community Collaborative.” Still mother described her role as “trying to get the families recognized as an important piece at the table, it isn’t treatment *at* us, but treatment *with* us.” Another mother said that she and other parents were “raising awareness and helping change systems.” Yet another mother shared how she understood her role at these meetings:

Our role as a parent advocate was to, bring to the table what the family’s concerns were, what that child was goin’ through, and to make sure that everybody on the table was on the same page—around the table was on the same page and everybody was headin’ towards the same goal—instead of having five or six different agendas, five or six different players around the table, you know, pullin’ and pushin’ the family this way, pullin’ and pushin’ the family that way. You know, look, you all are involved, you know the other one’s involved, so let’s get together, see what we have—what are you workin’ on, what am I workin’ on, how can we combine this together to make it easier for this child and this family.

Another parent said that through participating in policy-making, “We were trying to get as many parents as we could sitting on the collaborative so there would be that voice too, and not just one parent voice at the table for every parent.” This parent also that she perceived the role of parents “was also were to come back and bring the information to the support groups so that the parents knew what was happening and their voice could be heard back at the table for the ones who couldn’t be there.” This mother continued:

I think we got to the point where we were accepted at the table umm and of course we were needed because the grant required us at the table, ah, so they finally got to the point where I felt like we were more accepted than just that requirement that they had.

Still another parent stated:

But I would dare say about eight months into being a parent advocate, we'd sit down as the parent group along with the county collaboratives . . . and described to them what kind of needs these kids were facing and how they was—[this information] didn't seem to be available anywhere else.

Another mother expressed a similar sentiment:

But, um, I'm just glad that SOC came about because it brought out—out of the closet a lot of the things that were being taken away from the kids and, the kids couldn't do it for themselves what the parents needed to be doing. So, the parents back then, were involved enough where they could speak up for the youth and get things done.

Summing up the experience, one parent said: "Our voice mattered."

After claiming their place on policy-making boards, parents turned their attention to the opportunities provided by the grants to help transform the attitudes and behaviors of the providers with whom they interacted. The following set of quotes speaks to these actions. As explained in previous sections, and as they often stated, parents felt that providers treated them with little respect and that the providers had little understanding of their lives. One mother shared her desire to change how services were delivered by providers:

And, um, I just got involved and I wanted to go beyond working with families. I wanted a broader perspective of training, cause I got so fed up with DSS [Department of Social Service] workers, with the Department of Juvenile Justice, with [behavioral health care] workers not understanding what these families were going through, so that's how I got involved in training.

Another mother voiced a similar wish:

See that's what I loved about doing the system of care trainings...because really having—'cause, it was predominantly with professionals, really trying to get them to understand that because they would say the same spiel with the parents but—it wasn't like a lot there, and I think, I think they thought they could fool parents into thinking they cared.

Another parent described her training contribution: “So, I like to think that behind the scenes I changed some attitudes about the parents, I changed some attitudes about how to work with families.” Another mother shared a similar statement:

I mean, you know, that's one thing that kept pushin' me harder and harder and harder and gettin' me deeper into what I was doin' because I seen that kind-a reaction, you know from the people that these families were supposedly be workin' for 'em, but it seemed to me that they were just tryin' to push 'em out, get 'em done as quick as possible, you know, so we can go and deal with the next case . . .

A similar comment by another parent confirms some of these feelings: “[It was important] giving parents' permission to acknowledge, and hang in and work toward what they saw was needed for their child.” Another parent described similar feelings about “helping families deal with that and recognize and see their own power and strength.”

Another mother recalled:

‘You know, this [grant] application said that you should be providing support groups and that you should help us start a family organization. And you should be asking parents what they want and what they need. You guys [professionals] aren't doing that.’ And so, that's when some of the perceptions changed because, it was like, ‘Wait a minute, we don't want to change. What we are doing is working. Why should we, you know?’ So I think in the beginning the perception

of having parents involved was really good, especially when I first got involved. It was a very loving relationship. Ha-ha. And then it became a love/hate relationship. Oh, I think I was exiled.

Although participants summed up their experiences in several ways, every one of them was pleased that they had had an opportunity to make a difference and that they were provided with the knowledge and support systems to battle stigma, the helping professionals, and their own sense of powerlessness. The following quotes encapsulate particularly well how the parents described their experiences. With laughter in her voice and a touch of pride, one mother shared that: “After I got involved with [the parent organization], it was just 10 times worse, because they didn’t like the parent group because we were so boisterous. You know—and we stepped on their toes a lot.” Another mother described her experiences as “exhilarating.” Yet another mother said that the experience had been:

. . . very rewarding, I guess would be a good word. And I learned life lessons, life skills that I still use today. So . . . I mean it was just wonderful . . . I love helping people. I love helping people discover their strengths and support[ing] them. I really, I love that. I also felt empowered. And I really felt useful.

This theme was echoed by another mother who shared that the SOC provided her with “advocacy and voice and to be able to speak up so that you can improve services.” Another mother said: “The most exciting thing for me was helping parents find their voice.” Still another mother stated: “I made a commitment to do everything I could and I had the opportunity, passion and opportunity.” Another mother sums up her experience: “It was aggravating, awesome and exhilarating.”

Another mother shared that when she found her voice, “They gave, the SOC family support piece gave my voice, so that I could begin to advocate effectively for [my daughter], and know how to navigate all of these systems to get what I needed.” Another mother said, “In a lot of ways, I’ve benefitted and I think my family has benefitted tremendously.” Another mother summed up her transformation:

Just bumping around from place to place and finding things in isolation, I made a vow that no other parent would have to struggle in isolation and alone. It seems so scary when you feel you are hanging loose, out there fighting for your child’s life. You just want to make it right so that it could be different and better.

The last quote represents what I heard from every parent I interviewed: “The SOC grant gave us the opportunity to do it.”

### **Conclusion**

Children’s mental-health services are fraught with challenges for providers, parents, and the children themselves. The quotes I have included in this chapter from the participants reflect how publicly funding helping systems did little to assist them in finding services for their children. In addition, and worse, the systems that were supposed to be helping these parents functioned as sources of blame about their children’s mental health challenges, devalued them as parents, and disrespected them because of their location on the socioeconomic ladder. Worse, it often did not provided needed services. The SOC demonstration grants were designed to help transform these systems so that they would be more equitable and effective. Through their involvement with family-run organizations that were mandated under SOC grants, it appears as if the

parents were the ones who were transformed. The quotes from the participants tell the story of an experience that moved them, as mothers, from help seekers to help givers; in the process, they found their voice, identity, agency, and power. It is also interesting to note that every one of the mothers whom I interviewed is still working on behalf of other families who are raising children. Several of these mothers are working in paid positions, so their volunteerism has become a career, while others still work as volunteers to improve the lives of others. The impact of these people's participation in family-run organizations under SOC has been compelling, real, and sustaining. In Chapter V I will explicate the components of family-run organizations that are necessary if such lifelong transformations are to be achieved, and will also view these transformations through the lenses of feminist and empowerment theories.

## **CHAPTER V**

### **THEORETICAL ANALYSIS OF FINDINGS**

The subject of the debate regarding providing assistance to families centered on who is deserving and who is not deserving of the public's support. The population targeted by the debate is the very population that is most vulnerable; moreover, their voice and their perspective remain largely unheard as others determine their fate. Many of these people are women with limited financial resources. This is true both for people with mental health challenges and for those who care for them.

A low-income mother raising a child with mental illness is too often caught in the vortex of needing public services, battling with negative public perceptions of the mentally ill, and trying to raise a family. The barriers to receiving help are steep and the blame for these children's illness is placed solely on their parents; most often, the parent most responsible for care and most vulnerable to blame is the mother. The intersection of race, class, and gender, coupled with the need to access a provider-driven system, robs such mothers of their power, voice, and identity. This lack of voice, and the accompanying feelings of powerlessness, is not unique to the parents in this study. The messages of devaluation have been woven into the language, values and policies of formalized helping systems in the U.S. since their inception, when they first categorized those in need as deserving or undeserving (Abramowitz, 1996). Mothers with low incomes who are raising children with mental health challenges are placed into the



“undeserving” category, and they often absorb all of the negativity directed at them. Mothers must cope with being blamed for their children’s negative behaviors, fight the stigma associated with mental illness (Hinshaw, 2010), and navigate a fragmented and inadequate system of support (Waxman, 2004), often with little emotional and social support. The SOC demonstration grants extolled a new philosophy and approach to children’s mental health services in order to help change the dominant paradigm.

The purpose of this study was to understand the lived experience of parents who staffed family-run organizations funded under SOC between 1994 and 2011 in a single state. The two theoretical constructs that undergird this study are empowerment theory and feminist theory, with an emphasis on the role of identity (Groleau & Zelkowitz, 2009); specifically, a) identifying oneself as empowered (Zimmerman & Perkins, 1994); b) using voice, defined as the ability to identify your location in the social strata and to speak from your position about your position (Collin, 1989 & 1991); and c) agency, which refers to taking measures to change the current situation through self-directed actions (Ahearn, 2001; Kabeer, 1999; Villaverde, 2008). Three research questions guided this study:

1. How do parents or caretakers raising children with mental illness and staffing family-run organizations under SOC funding describe and make sense of their lived experiences before and during their involvement with the organizations?
2. How are these perceptions gendered, and how does their gendered nature reveal ways that participants’ roles as women are salient?

3. How can the lessons learned from these parents inform the model of family-run organizations under SOC that are staffed primarily by low-income mothers?

In this chapter I attempt to answer these questions in light of the findings detailed in Chapter IV; describe the overlapping elements of empowerment and feminist theories that explain the transformations experienced by these parents; and highlight the role of gender in their experiences. Last, I discuss the significance and limitations of this study.

### **Making Sense of the Lived Experience**

As I listened to the parents, describe staffing family-run organizations, they described their experiences as empowering and transformative. More than one used the word “empowerment” to describe how she experienced the phenomenon of staffing a family-run organization. Others used words that conveyed the same meaning, for example, some said things like, “SOC gave me my voice.” The women I interviewed spoke frequently about this transformative experience and its impact on their lives, as well as on the lives of other families. The comparison data in Chapter IV that detail parents’ experiences prior to and during their involvement in a family-run organization leaves little doubt about how parents viewed their experiences: it is their interpretation that they became empowered. Because this was also my interpretation, I wanted to glean from their stories the necessary conditions that led to this sense of empowerment.

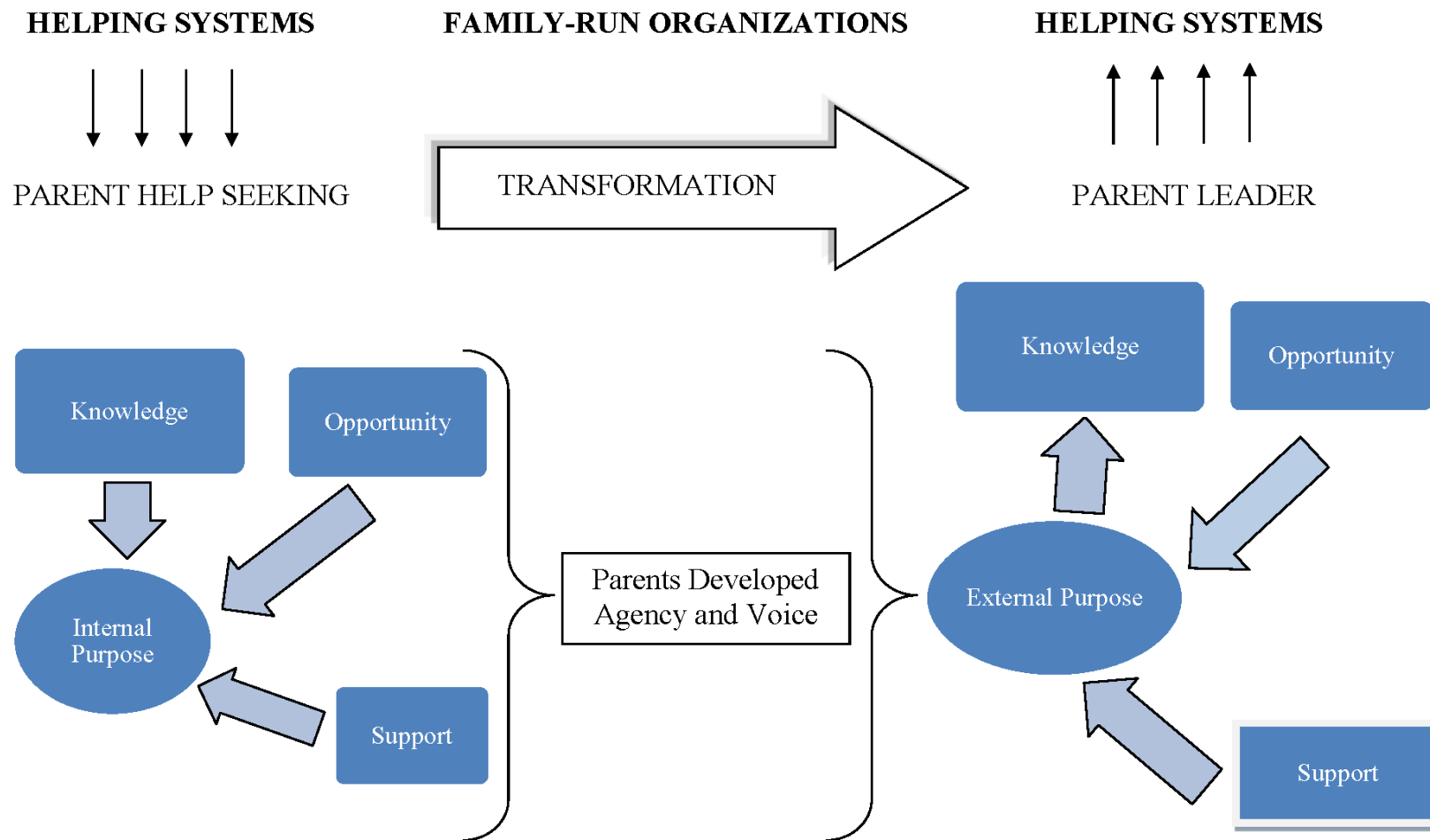
As I have interpreted the data, it is my conclusion that (a) having a compelling purpose; (b) gaining knowledge about professional helping systems, children’s mental health, and the rights of children and families within these systems; (c) developing a

support system, particularly of people who shared a similar lived experience; and (d) taking opportunities to participate in decision making as mandated by the SOC grants, all combined to transcend “what was” and created “what is.” By utilizing these four components, parents transformed from help seekers to help givers and ultimately to parent-leaders.

### **Transformation Model**

The model in Figure 2 displays the components that led to the transformation of the mothers whom I interviewed. Once these components were in place, the mothers found their voice and agency, but did not reduce their efforts when they began to fulfill their original purpose. Instead, their compelling purpose expanded and the first-generation mothers (i.e., those who had initially been selected by professionals to participate in the nascent grant process) proceeded to apply these components to the ways they helped other families. The transformation mode was now regenerative, that in the span of their four- to six-year grant periods they were recruiting and training both a second and a third generation of parents via the same components that had led to their empowerment.

The transformation model has two components that mirror the data; they contain primary differences with regard to (a) compelling purpose; (b) who is delivering the primary components; and (c) the direction of stress. The first component reflects the attributes provided by SOC grants to parents who were seeking help for their children.



**Figure 2. Transformation Model.**

If we start on the left-hand side of the model, we see the formal helping system is pushing down on parents who are driven by the internal purpose of finding support for their children. They are involved in a system that was pushing down on them in ways they feel powerless to change. With their compelling internal purpose of helping their children driving them, these parents changed their environments by taking advantage of the knowledge and training provided by the SOC grants, the opportunity to participate in decision making for their children, and the support that coalesced through the family-run organizations.

**Purpose.** Parents began their forays into the SOC demonstration grants with a drive to seek help for their children. Theirs was an internal purpose focused on their children and families. This purpose drove them to find support for their children and also allowed them to endure the negative experiences associated with the helping systems they encountered. It was often due to their persistence that these parents were known to providers and thus were tapped to fill the requirement of parent involvement in the SOC grants. The data revealed that, through their experiences with SOC family-run organizations, these parents acquired knowledge about children's mental illness; the laws, policies, and procedures that governed the helping systems; and their rights as parents within such systems. This knowledge alone, without being connected to the other two components of the opportunity to participate in their children's care, plus a strong sense of social support, might very well have helped the study participants to acquire services that were more useful to their children and themselves. Yet, when these components

were combined, a cyclical model was set in motion that started a parent movement in each local site.

**Knowledge.** The trainings on children's mental illness, medications, system navigation, and the laws that governed these systems, were eagerly received by the parents in this study, who often mentioned the importance of acquiring the knowledge necessary to help their children. Once parents began learning about systems and policies, they often took it upon themselves to learn more. As the data revealed, once parents felt the power that came from having knowledge, they began to assert their opinions about what they wanted for their children. They began asking smart questions and expecting full disclosures. As they learned about their right to participate in decisions about their children's care, they began to request full inclusion; now, they knew when they were not getting it. Last, as parents learned professional jargon and medical terminology, they began to feel as though they could communicate on more of an equal basis with professionals. This knowledge allowed the mothers who participated in this study to engage fully and to ask for those opportunities.

**Opportunity to participate.** The uniqueness of SOC grants was that they mandated parental involvement in all aspects of the grant work: planning, implementation, evaluation, and participation on policy-making boards. Parents no longer had to ask to participate. It was a requirement that all local mental health center organizations that accepted SOC funds in the form of demonstration grants had to enact significant inclusion of parents or risk losing the federal funds.

Prior to their acceptance of SOC funds, none of these sites had bought into the philosophy of family partnerships in any systemic manner. These grant requirements opened the door for parents who had previously been excluded, and who may not have seen themselves in this type of role due to their life circumstances. Initially, many of the mothers would not have dreamed that there could be roles for them outside of caring for their families. However, the grant mandated that they (a) start a family-run organization; (b) participate in care and treatment of their child; and (c) participate in policy-making bodies thus opening a door that previously had been hidden from them.

Parents now had the backing of the federal government, through the SOC grants, and this backing confirmed their worth from a large, external source: the federal government believed that parents could and should do these things. This mandate allowed parents to see themselves differently; it gave them a reason for staying at the table and the ammunition with which to push back against both the status quo and the professionals who may not have welcomed their participation. However, parents often felt isolated at these meetings and on the committees that were filled with professionals. One parent referred to herself as the “token parent”; this status was alluded to by many other study participants. Yet, most of the parents stayed on these committees. I believe that the type and amount of social support they received from each other helped them to hold their ground.

**Support.** The data demonstrate that the type of social support that was most beneficial to parents came from their peers (i.e., other parents who were also experiencing the challenges and joys of raising a child or children) with mental health

challenges. Through this social support, parents had sounding boards and groups of women who were “on their side.” Every mother I interviewed confirmed that 85–95% of the people who participated in the family-run organizations were women. Clearly, these groups of like-minded women could help balance the power differential that came from being a lone parent battling a large, unyielding bureaucratic helping system. When parents began to question their own sanity or ability to care properly for their children, the support system became the counterbalance that mirrored a different, more balanced picture of the reality they were experiencing. As this social support system reduced isolation and bolstered confidence, these parents created their own community narrative that countered the prevailing stereotypes of who they were as people and as parents. To recall a quote from Chapter IV, one mother describes her experience:

Well, first of all, it was the relationship [with other parents] that was involved and getting’ their perspectives. You know, and it gave us somebody to be with that knew what we were going through every day, ourselves as parents.

**Voice and agency.** Issues of agency and voice are critical in the empowerment process (Kuokkanen & Leino-Kilpi, 2000; Zimmerman, 1995) and in feminist literature (Ahearn, 2001; Kabeer, 1999; Villaverde, 2008). The parents who participated in this study interpreted their actions as having value, a role in changing perceptions about parents raising children with mental health challenges and influencing helping systems. They now saw themselves as agents of change. Prior to their involvement with the family-run organizations, parents reported that they felt powerless not only to help their children but also over the systems that influenced their lives.

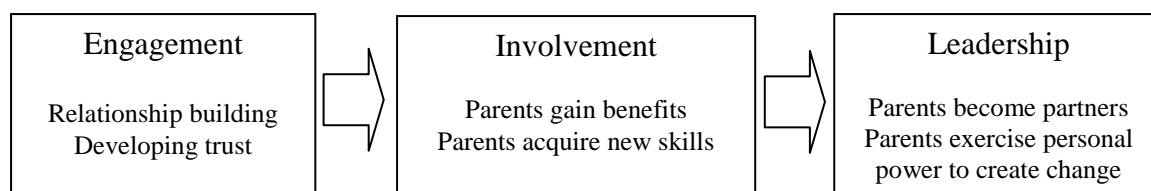


Agency, as defined by Kabeer (1999), is the ability to establish goals and act upon them. Agency is linked to empowerment theory, particularly the behavioral component of individual empowerment (Ahern, 2001; Kabeer, 1999) as it results in observable actions. Yet agency is not synonymous with the word “action”; it means more. Agency is purposeful action. It stems from people tapping into their inner power and using it with meaning, motivation, and purpose (Giddens, 1986; Kabeer, 1999). It was the combination of knowledge, opportunity to participate, and social support that led to the agency and voice of the mothers in this study. Bandura (2000) sought to explain this when he wrote:

People do not live their lives autonomously, as many of the things they seek are achievable only through socially interdependent effort. People have to pool their knowledge, skills, and resources; provide mutual support; form alliances; and work together to secure what they cannot accomplish on their own. (p. 75)

Involvement in family-run organizations helped parents move from being “just a parent” seeking services to functioning as “parent leaders.” The National Resource Center for Community-Based Child Abuse Prevention describes a parent leader as “a parent who is facing the challenges of parenting in our society, representing a ‘parent voice,’ and functions in a variety of leadership positions which result in better outcomes for children and families” (second paragraph). In other words, parent leadership is about the ability to create change rather than to merely participate in change. Family Support America (1999) has suggested that there is a continuum of parent/family leadership development that includes engagement, involvement and leadership.

Figure 3, which presents the trajectory for many of the parents in this study as they transformed into parent leaders and help givers.



Note: This continuum of parent/family leader development is a modified version of an illustration published by the Family Support Network (1996).

### **Figure 3. Levels of Parent Engagement.**

The right-hand side of the transformation model depicts the transformed parents acting as leaders, replicating the left-hand side of the model, and creating an ever growing cadre of parents who were traversing along the Levels of Parent Engagement model in Figure 3 and emerging as parent leaders. The quotes from the mothers revealed that they felt their power and wanted to share it with other parents. Through the experience of staffing a family-run organization under the SOC, parents' found their voice and used that voice to act on behalf of their own families. Parents then acted to improve services for all families. They engaged with other parents, and acted as teachers, mentors and peer supports. They replicated what the SOC grant provided for them, knowledge opportunity and support, with other parents. These first generation parents, those who were tapped to as the initial participants in the SOC grant were now passing on the model that worked with them; thus creating second and third generation of parents who were finding their voice, claiming their power to the benefit of themselves and other

families. As the quotes reveal, it was important to the original parents to pass it on to other parents. This became their new external purpose.

Voice and agency are salient points in both feminist theory and empowerment theory. Voice refers to the parents' ability to tell their own stories. This is an important component of the empowerment process (Zimmerman, 2000). This story telling helped parents make sense of their experiences, and recognize the value and impact of those experiences. Through their experiences working with the family-run organization helped parents rewrite their personal narratives. They became leaders and advocates, people who had expert knowledge on their child's needs, and people who had to know the system policies and laws better than those within the system. As one parent said, "I found my voice." Another mother shares, "SOC gave me my voice."

Creating change is about agency; the ability to act. This is a core component of empowerment theory and feminist theory. Parents became advocates for their children and then, for all children and families. The parents worked tirelessly, fueled by their passion to help first their own family and then, other families. Both empowerment theory (Sadan, 1997; Zimmerman, 2000) and feminist theory (Banks-Wallace, 1998) speak to the goal of moving people from a state of powerless to a state of being socially aware and having the ability to make choices and decisions. It is also about having a voice in the choices and decisions. We heard parents share the changes they made in the lives of their children, particularly to the professional treatment plans prescribed for their children. They also worked to change system and professional practice. The lessons that parents learned for themselves and then provided to other families lasted well beyond the grant

funding. In the words of one parent, “I learned life lessons, life skills that I still use today.”

**Gendered concepts of identity, standpoints, and power.** Parents raising children with mental health challenges often adopted the negative meta-narratives told about them and their children. An often repeated theme in the literature and in this study was that parents felt blamed for their child’s mental illness. According to many professionals, family members, and sometimes according to the parents themselves, they were the cause and the culprit of all of their child’s problems. Parents often felt at the mercy of the powerful professionals. As parents adopted these negative meta-narratives, their voices, once again, were silenced as they adopted an identity that had been handed to them by the circumstances of their child’s illness. This silence also eroded their sense of power (Bloom, 1998). As they stood alone, washed by the tide of the services, they had little support and no reference point by which to examine the identities they had adopted. The family-run organizations to which they belonged became that reference point.

***Identity.*** All people have multiple identities, and women who are mothers, it is this identity often stands out (Gilligan, 1982). For the participants in this study, finding support for their child was an overriding purpose; thus it was their identity as a mother that took precedence. Their identity as a mother raising a child with mental health challenges was where they now drew their power. This identity as “a mother” also allowed them an opportunity to connect with other mothers as equals. As shared earlier, some of the parents interviewed in this study had degrees from colleges, had started

businesses, and one even belonged to a higher socio-economic status, yet their experience as a mother seeking services for her child with mental illness combined with their empathy and caring for others became the equalizing factors. This compelling identity seemed to precede over others as no participant interviewed reference power related to class, and/or gender on their own. When I probed further regarding why they thought some of these power inequities were happening, none of the participants referred to their status as a woman, their race or socio-economic status.

However, through their experiences of staffing a parent-run organizations the mothers in this study discarded the negative identity that had been reinforced through durable stereotypes (Bloom, 1998) and owned a new identity of their making and choosing (Mankowski & Rappaport, 2000; Rappaport, 2000). Through training and support of other parents, the mothers changed the master script and changed their reality and the reality of many other mothers. The participants were able to shake-off the dominant cultural narrative and adopt a new narrative, that is the narrative of someone who has power and resources to help their families and others people such as other families, practitioners, and policy-makers. Parents moved from being “just a parent,” to becoming “parent advocates,” people who helped other families, and used their expert knowledge as a parent to help inform the human service systems that served them. In most all the interviews, the parents continual shifted back and forth between the stories with their own child, and with the stories of other parents with whom they were working. For me this signified that these two identities are intertwined in such significant ways that

the parents themselves do not often differentiate between these roles. Bloom (1998)

argues:

Examining subjectivity in women's personal narratives is to redefine what it means for women to write, tell, discuss and analysis their life experiences against the backdrop of the prevailing discourses that seek to silence them. To change the master script is to change reality; to change reality is to participate in making a history different from the one the status quo would produce. (p. 64)

The social support provided by the other mothers raising children with mental health challenges was critical in the identity shift. Avest et al. (2008) argue that identities of individuals, communities and organizations are linked and influence each other. Bandura (2001) supports this claim that people do not live their lives autonomously, as many of the things they seek are achievable only through socially interdependent efforts. People have to pool their knowledge, skills, and resources; provide mutual support; form alliances; and work together to secure what they cannot accomplish on their own. Therefore, our identity, or our sense of self, is developed in connection with other people. This speaks to the importance of the both the knowledge and support components of the provided by the SOC grants that led to the transformation.

***Standpoints.*** This support of other parents allowed for maintain, reaffirm and speak from their multiple standpoints. The parents' life experiences structured their world-view and understanding of how the world worked for them (Hill, 1991; Swignoski, 1994). The SOC grants validated parents speaking from their own standpoints regarding their own experiences and socially situated knowledge as women, from a lower-economic

class, bearing the stigma of raising a child with mental illness and for some their race.

The significance of these constructs is detailed in Chapter II.

Professionals now were required to listen to the mothers talk from their standpoints. Although the professionals had to listen to the parents speak from their standpoints, they did not always hear. When there was no affirmation that these standpoints had relevance by the dominant culture, through their social support, parents had a sounding board, and group of people who were in essence, “on their side.” Parents had access to a support group of other parents sharing the same situated knowledge and facing the same challenges of running an organization and participating in system change efforts. This support of other parents allowed for maintain and reaffirm their standpoints. Through this experience of staffing a family-run organizations, the parents have reframed what the dominate culture had identified as deficits, into strengths. Although in most ways parents were acting in a professional capacity, they readily and often distanced themselves from adopting this word from themselves. Those parents who moved into a professional role within an organization still frequently referred to themselves as a “parent.” For the parents, this word implied their standpoints and situated knowledge. In the quotes shared in Chapter IV, parents continuously refer to themselves as parents even though they were performing roles that professionals were being paid to do. As one parent summed it up, “I still felt like I was just a parent, but a parent with a lot more tools in my hand that could act on a professional level.” Even though parents speaking from their standpoints were validated by the grant, the parents quickly learned they needed to also adopt the language and style of the dominant culture. Parents became adapt at in

essence at code switching depending upon whom they were speaking to and in what cultural context. This resonated in several quotes by parents including, one mother sharing, “Oh yeah. (laughter), yeah, you have to learn, the biggest thing that I had to learn at first was to learn the professional languages and meanings...” Another mother shares:

Well that’s what I learned was it didn’t serve me well. [to cry]. I needed to be able to tell the story in a factual way. I needed to be, and for impact, uh, I couldn’t be all over the place. I couldn’t be crying, I couldn’t fall apart. I needed to be able to be on their [professional] level and tell it in a practically professional way. I couldn’t tell it as a parent.

The mother continues that she had to:

Put on this persona that matched. You have to be able to be here with your service provider, otherwise you’re dismissed. So I had to be able to tell that story eye-to-eye, in language that he understood, and then to be able to you know, say uh yes, this is what I’ve done and I thought that you know, I had to be able to really, uh, go back and, and confirm that I had done things that they would have done that any reasonable and practical person would have do. And uh, you kinda have to uh, confirm your sanity as you are pleading your case, and you have to convince them that you are sane, while pleading that your child might possibly not be.

In addition to adopting the professional language and manner of talking, parents had to adopt their dress in order to be heard. One mother shares:

It was very important when I went to meetings to dress professionally but I always made sure that when I met parents I dressed as normal. Um, when I went to meetings [with professionals] I just had to maintain that because they do not respect you if you wear jeans and a t-shirt. And that’s school mental health- that’s just across the board. You know, that’s just life.



**Power.** Recognizing the power differential and having to change their ways and speaking and acting to access what the power structure had to offer was a skill the parents leaned. However, for many of the mothers from their standpoints, personal power was derived from the process of helping. Through helping first their own families, and then other people, the women in this study found their sense of self, which had most recently been defined by others and then themselves as “just a parent,” and not a good parent at that. Helping others became the mechanism by which their identity as a person of worth and value grew, and a sense of self-fulfillment emerged. This sense of helping is now external to them and their families, and has shifted to a larger worldview of changing the experiences of other families. As the quotes in Chapter IV reveal, it was the concept of helping other people that made the parents in this study feel empowered, or powerful. This notion of helping others as an expression of power is consistent with the literature on how western women assume power and leadership roles. Women leaders are often seen as caring and relational (Bruner, 1999; Grogan, 1999; Miller, 1987; Tallerico, 2000). We saw the women in this study replicating the positive benefits they received under the SOC with other families. According to de la Rey (2005), these actions are consistent with how women express power and they view leadership positions. De la Rey (2005) writes that “Women are also more likely to lead from behind . . . , and to be encouraging of participation, sharing power and information” (p. 5).

**Side effects of transformation.** Throughout this dissertation, I have shared the positive impacts of staffing family-run organizations upon the mothers who were interviewed during the study period. However, there were also other outcomes that these

parents had not anticipated; nor do I believe the funders anticipated them either. For example, many of the parents found careers outside their homes that are related to the work they did in family-run organizations under SOC. Seven of the eight mothers whom I interviewed are currently in paid positions that involve education and advocacy roles with other families. One continues to volunteer her services and share the knowledge that she learned while staffing a family-run organization. All of the parents still refer to themselves as “parents helping other parents” and continue to share their standpoints readily with other parents as a way of finding commonality and a creating a shared understanding.

Another side effect of transformation was the demise of the family-run organizations themselves when they were either defunded or taken over by other, professionally run organizations. Many of the parents did not anticipate these outcomes, and when they did they were powerless to change them. They experienced hurt and anger when the organizations were initially defunded. Some parents attributed this defunding as a response to the numbers of parents who were now pushing against the system. According to one mother: “They [the professionals] were frustrated and they thought that the families were causing trouble, and, um, being too demanding and things like that.” A second parent shared: “Well, I think they just realized that parents were not gonna step down, to the issues that were at hand.”

The SOC grant requirements meant that many professionals became actors in these new kinds of practices, instead of having complete control as they had before, and many of the professionals both resented this change and rebelled against it. However, I

believe that some professionals were forever changed for the better by the transformations that happened to parents. The professionals who were able to hear the parents speak from their standpoints and understand the knowledge being shared with them now had access to a worldview that they had never seen and, in some cases, had not known about. I know that I am one of those people.

The last side-effect of parent empowerment that I became aware of was the tendency of mothers of children with mental health challenges to join together, even though the system they are fighting is a silo. Governmental helping systems perpetuate the inequalities of all types of people, yet these mothers did not band together with people whose situations were vastly different from theirs. Perhaps their histories of fighting for services for their children resulted in a sense of competition with other mothers whose children had different, albeit equally urgent, needs. Had all of these mothers and other marginalized people joined together to fight against all inequalities, the results might have been very different.

### **Summary and Significance of Study**

The quality of children's mental health services remains a serious concern for families, providers, and policy makers (Waxman, 2004). By the 1990s, the preponderance of negative outcomes for children with mental health challenges (Wagner, 1995), and the co-occurring strains on their caregivers (EvaluBrief, 2006) warranted substantial federal funding in the form of SOC grants. A core principle of the early SOC grants was the empowerment of parents through family-run organizations. However, for families who are raising children with mental health challenges, claiming their power and becoming

resources for other parents requires time, energy, passion, access, support, and skills. Efforts at parent empowerment are also impeded by the stigma associated with their children's mental illness (Hinshaw, 2005), parental stress that results from lack of services (EvaluBrief, 2006), and the dominant cultural narratives applied to them as people in poverty (Bloom, 1998).

Given that family-run organizations have been promoted and funded for many years, we know little about them as a vehicle for parent empowerment; even less is known about the long-term impact of families' involvement in mental health system reform. In this qualitative interpretive phenomenological study, I have shared the voices of parents who staffed family-run organizations under SOC grants in a single state. As detailed in feminist theory, the voices of these mothers had been silenced by service-delivery systems and then ignored by evaluators, researchers, funders, and society at large. In this research project, I have privileged parents' voices as a way to make meaning of their experiences as women and mothers; add to their positive concepts of self-identity; and refute the master narratives—all while presenting lessons that can inform other families as well as providers and policy makers.

In a much earlier section of this dissertation, I described family-run organizations as the penultimate in parent empowerment. For the parents who participated in this study, it proved to be true. Through work in developing family-run organizations, parents' roles shift from acting as recipients of services to now also being providers of services to other families and resources to practitioners. Through this new role and the sense of empowerment, new identities began to form. Parents took a seat at the policy

table with providers and were viewed as people with valuable information. The last question asked in this study is regarding the continuation of the personal transformations last over time. It is clear that it does. Almost all of the parents I interviewed continue to provide services to other families, formally either in a paid position, or informally in a volunteer and friend capacity. The mothers who participated in this study and have been forever changed by their role in staffing a family-run organization, and in the process so have their families.

The use of interpretive phenomenology is consistent with both feminist theory and empowerment theory. The themes and stories that are the threads running through the participants' narratives form the component parts of a community narrative. By constructing a community narrative, the participants highlight their own stories continuing to shape their identities in positive ways, thereby counteracting the negative dominant cultural narratives that were previously applied to them. Furthermore, presenting their stories as a collection, rather than as a case study based upon an individual narrative, adds weight to the findings. This story is a collective story formed by the individual stories of each participant. As such, it cannot be dismissed as the opinions of "an isolated parent," which often happens when individual parents speak up. Through these research findings, policy makers and other stakeholders can develop a better understanding of the role of family-run organizations as a vehicle for developing parent empowerment, and the extent to which the funding of family-organizations has sustained parent empowerment over time.

Through the experience of staffing a family-run organization under SOC, parents found their voice and used that voice to act on behalf of their own families. Parents then acted to improve services for all families. They engaged other parents and acted as mentors and peer supports. They replicated the cycle of their own empowerment that the grants provided them on behalf of other parents. These parents are now providing knowledge, support, and opportunities to create an ever-growing movement. Parents became advocates for their own children, and then for all children and families facing a similar situation. These actions are consistent with the activities of empowered people as well as with feminist literature on how women experience power. Both empowerment theory (Sadan, 1997; Zimmerman, 2000) and feminist theory (Banks-Wallace, 1998) speak to the goal of moving people from a state of powerless to a state of being socially aware, having the ability to make choices and decisions, and having a voice in these choices and decisions. The lessons that these parents learned for themselves and then provided to other families have lasted well beyond the SOC grant funding. In the words of one parent, “I learned life lessons, life skills that I still use today.”

This study is important because it provides data from the parents, themselves, to support this claim; such data was not previously available. This data adds credence to suppositions made by professionals and the extrapolation of research done with other populations. As stated in Chapter II, the national evaluation of SOC did not collect data on family-run organizations and the parents who staffed these organizations did not have opportunities to speak about their experiences. The little data that is available demonstrates that family-run organizations are not sustained post-grant-funding, or is the

principle of parent partnerships fully implemented when there is funding. The parents I interviewed staffed nine different family-run organizations, but only one is still operating; most ended when the demonstration grants were no longer available. The stated goal of the initial grants was that the state and/or county site would continue both SOC's and family-run organizations. But these outcomes did not occur.

This study shows the transformative power of the family-run organization model through a gendered lens that examines the roles of class, race, and gender. In just a few years, mothers with limited incomes went from feeling powerless to feeling powerful, from feeling devalued to valuable. These feelings were accompanied by actions that speak to the behavioral component of empowerment, in a manner that is reflective of the unique ways that women behave in roles of leadership and power. This is a study about the power of the human spirit. The quotes from parents, both before and after their involvement in family-run organizations, demonstrate all of these qualities.

### **Study Limitations**

Qualitative studies, in particular interpretive phenomenology, have several inherent limitations. This study had a relatively small sample size. Although it was well within the range of participants for an interpretive phenomenological research study (Smith et al., 2009), it limits generalizability to a larger population. The data collection method, focused interviews, is also a limitation. Interviews are subjective because participants reveal only the data that are important to them and share with the interviewer only what they are willing to share. Subjectivity is thereby increased, as it is the interviewer's responsibility to interpret the data. One could even argue that that my prior

experience with the participants was a limitation because it held a bias, even though I managed this bias through reflexivity. Another limitation concerns my request that participants remember an experience from their past. However, although time had passed, the participants' memories of how they became empowered remained vivid. Last, this study focused on parents who experienced the phenomenon of family-run organizations in a single state. It is reasonable to assume that other states may have implemented their SOC programs differently, and parents who staffed those programs may have experienced different effects.



## **CHAPTER VI**

### **RECOMMENDATIONS FOR ADDITIONAL RESEARCH**

Although the intent of system policies regarding parent empowerment is explicit, the theoretical underpinnings, implementation processes, and outcomes are less so. Unfortunately, a commensurate shift does not seem to have occurred in knowledge about organizational systems, the roles of providers, and the system processes and structures that lead to empowering outcomes for those who are receiving the services. Below are some recommendations for future research.

#### **Organization of Human Service Systems**

Examining empowerment through an individual perspective as a mechanism for social change, is limiting. According to Langton (1978),

The unfortunate paradox of our system [is that] that only those at the lower end of the social hierarchy need to participate in order to generate power. Individual citizens are often asked to participate at considerable personal sacrifice, only to find themselves as powerless as before. (p. 113)

Liberating an oppressed group of people does not necessarily lead to change within the systems that served them. These concepts are related but are not synonymous. System empowerment is inextricably linked to individual empowerment; a discussion of one without the other creates an incomplete and distorted picture. As parents reside outside of the system and feel the need for change, professionals are inside a hierarchical system that is often resistant to change. Furthermore, professionals are a product of a

system and the system seems to work for them. For example, as “outsiders,” parents do not set policy. Instead, policy makers set the values for the system and then codify them into the language of policies (Goodsell, 2006). Historically, those that determine policies also hold the power to rescind them and to allocate or withhold necessary resources (Hardina, 2003). In short, power, authority, and control are maintained by those who “grant” the services. For their part, parents serve as social activists and partners in service delivery at the complete discretion and pleasure of those who hold the power.

Ironically, the human service system in the U.S., which has created dependency through its policies and practices, is now mandating empowerment using identical power and organizational structures as in the past. These systems dictate the rules, which can either favor empowerment or not. Therefore, one area for further exploration is the theoretical underpinnings of the service system, which as it is now structured appears to negate its professed ideology of empowerment. Within the empowerment process in the human service system is the expectation that those who are most reliant upon the system will make the most demands and that they will change the system from the “outside.” One example is the parent movement that has grown around children with developmental disabilities (Turnbull et al., 2006). However, this movement was begun by predominantly White, middle-class women who already had access to knowledge and could forge their own opportunities through the resources granted to them by their racial and social status. Although these women struggled to obtain appropriate services for their children, in other ways they occupied a positionality of privilege and power. Their

struggle, which is unique to them, cannot necessarily be theoretically transposed to other populations.

When a mother who represents multiple inequalities such as status, race, and the stigma associated with mental illness, attempts access services for her child with mental illness, societal devaluation often comes into play. If this mother makes too many demands, she finds that a different set of rules will be applied to her: the system holds the all of the power and she holds none. The system has the power to impose sanctions, including removal of her child from her care, should a mother speak up too loudly or too often (Bradbury-Jones, Sambrook, & Irvine, 2008). This possibility appeared in the interview data when parents referred to their fear that their children would be taken from them due to their own behavior. Therefore, another area that begs further research concerns whether a system that is grounded in a hierarchical structure, with power centered at the top, and that is also grounded in systems thinking (explained below), can successfully assist the populations it serves in claiming their power, moving out of dependency, and advocating for social justice. Our current level of knowledge regarding empowerment at the system level fails to explain how this may happen. Organizational structures, policies, and practices can support or hinder the achievement of empowerment (Spreitzer, 1996). For human service systems, the bureaucratic model for setting and then implementing policies is explained by systems theory, which by its nature is counter to individual empowerment.

Pickel (2007) described the basic operation of large, bureaucratic systems as being effective when large, complex components are deconstructed into progressively

smaller units, according to the notion that each unit, together with all other units, makes a whole system greater than the sum of each of its parts. Ideally, the various parts of the system are linked to each other with standardized processes and applied uniformly. This procedure may work well for systems that deal with inanimate objects, but it becomes a major flaw in systems designed to serve children and their families, which are not standardized or uniform even when the people who are supposed to be receiving care have similar characteristics and the same diagnoses.

Systems such as human service systems contain regulatory processes and sensors in order to maintain their complexity and their equilibrium (Ager, 2007; Elder-Vass, 2007). These regulatory processes are rules by which the systems operate. Furthermore, the rules of these systems are known only to those within the systems (Cheater, 1999), a condition that leaves those being serviced by the system at a disadvantage when they try to effect change. Even in human service systems, the basic bureaucratic structure has remained relatively consistent for more than 100 years (Katz, 1996). Ager (2007) stated that human service systems “operate under a dense regulator thicket of regulations” (p. 98). Current colloquial sayings such as “navigating the bureaucratic maze” illustrate the regulatory nature of human services.

The linear thinking within systems strives to identify cause and effect. For example, according to systems thinking, one could logically infer that poverty is the cause of homelessness. Yet, we know from our own lived experience and from research that this simple causative relationship neglects many other inequities that can lead to homelessness, such as economic inequalities related to gender and ethnicity, mental or

physical disabilities, and substance abuse. This linear cause-and-effect approach cannot address these multiple inequalities, which results in people being served by these systems, being forced to operate within only one part of their identity at a time. This situation is what Foucault (1982) referred to as the “system of differentiations” and a core component of power relationships (p. 272). Powerlessness is a social problem, but it is often treated as individual problem (Sadan, 1997).

In human-service delivery, the approach to problems is to reduce any problem to its smallest denominator. When working with people, the smallest denominator tends to be on the individual level. Interestingly, this is the same denominator often used in empowerment. Reducing all problems and their solutions to the individual level feeds into negative stereotypes about people who use services and results in what is commonly referred to as “blaming the victim”—a theme that appeared multiple times throughout the interviews. Moreover, this approach negates the role of environmental influences that induce oppression and promote gendered and racist policies and practices (Nuebeck & Cazenave, 2001). Coupled with these issues are the organizational values that either support liberation or empowerment or buy into the dominant cultural narrative and are therefore punitive toward those who seek access.

### **Organizational Values**

Organizational values are those that guide the work of an organization. They are often contained in mission and vision statements and represent the directionality the organization strives to accomplish. The SOC grants were intended to infuse the SOC philosophy (Chapter II) into the organizational values of the professional helping

organizations that received SOC funds. These values were not uniformly incorporated or, unfortunately, universally shared within the organizations; nor were they fully understood or routinely implemented in practice via organizational processes (defined as the components of organizations that may or may not lead to psychological empowerment among workers).

Research has suggested that processes that lead to workers feeling empowered include access to information, support (Kieffer, 1984; Rappaport, 1995; Wallach & Mueller, 2006), and access to resources (Perkins & Zimmerman, 1995). Other components are the ability to advance within the organization (Rappaport, 1995), to share in decision making, to assume leadership roles (Foster-Fishman et al., 1998; Wallach & Mueller, 2006; Rappaport, 1995; Zimmerman, 1990; Zimmerman & Perkins, 1995), to share a common vision (Arndt, 1996; Spreitzer, 1997), and to experience supportive supervisory relationships (Wallach & Mueller, 2006) that result in workers perceiving their own competence, a sense of impact and meaning, and a sense of self-determination (Thomas & Velthouse, 1990; Spreitzer, 1997). As professionals on the front and mid-level directly interact with people accessing services, these values become even more critical in the empowerment process.

### **Role of Service Providers**

Providers of services have a significant impact on parents who receive services. As I heard from many of the mothers in this study, service providers are a critical component of the empowerment process (Sadan, 1997). Sadan (1997) stated: “The professional has to believe in people’s ability to learn and to change and, at the same

time, recognize that oppressed people are liable to possess the distorted consciousness due to their life circumstances” (p. 113). The practices that are used by professionals facilitate either empowerment or disempowerment of the people they serve, who most often are members of vulnerable and marginalized groups. Nonetheless, providers are often agents of personal and community empowerment. They can be catalysts, confer legitimacy, and provide resources and structure (Sadan, 1997). Providers can also disempower those whom they serve, however. Examples of both types of providers were given by participants in this study.

Several authors have drawn connections between worker empowerment and the ability to provide empowerment-based services (Bradbury-Jones et al., 2008; Gutierrez, Parsons, & Cox, 1998). These authors contended that workers need to feel empowered before they can empower others. Because a disproportionate number of care providers are women, they, too, live in the same gendered world. For example, as women, professional providers have often had no voice. Although they are front-line and mid-level providers, they do not set policy. The SOC requirement that parents have a voice can break the previously imposed silences placed upon the human service worker.

As I learned from the parents I interviewed, many individual providers are deeply committed to the authentic partnerships with the people they serve and to helping them claim their power. Professionals, who are often part of the social milieu, can engender or diminish individual and community empowerment. However, we do not know the characteristics and the differences between those providers who work to actively support

the empowerment of parents and those who do not and this would be another area for further research.

Although my research did not ask about the training given to providers about understanding the dominant cultural narrative and how their actions could either challenge or perpetuate it was outside the scope of this research. Participants made it clear, however, that adopting a professional persona was important in order for professionals to afford them a modicum of respect. It is not my understanding that the professionals now working under the SOC philosophy has been educated about the structural inequalities that impact not only services but also the lives of all women. Nor did it seem as if professionals have been taught to modify their practices in favor of empowerment-based approaches. Nonetheless, this new approach seemed to instinctively resonate with many of the professionals I heard about, in that they were assisting the mothers with understanding and navigating the system in significant ways.

If the characteristics of professionals that lend themselves to a more feminist approach were better understood, it would be easier to (a) recruit workers who feel so inclined; and (b) provide training and support to providers to help them gain the professional skills that support empowerment. This information would help decision makers make changes in professional practices to ensure that empowerment philosophies and practices are happening both inside the system, with providers, and outside the system, with parents. Changing the system from both inside and outside is critical to maintaining family-run organizations and empowerment-based practices. Assisting



helping organizations to modify their values and practices is critical to creating lasting change in the lives of the families they serve.

### **More Information from Parents**

More information is needed from mothers who have tried to start groups and succeeded, as well as from those who have not succeeded. Researchers should partner with families to describe and detail, from the family perspective, the necessary conditions for sustainability for family-run organizations. Furthermore, more is needed to understand the necessary conditions for success and sustainability of the organization. In addition, learning more about the type of parent who staffs these organizations can aid in both recruitment and retention of staff. Some research was performed on the sustainability of the Statewide Family Networks (Briggs, 1997), but much more is needed.

### **Conclusion**

Families are at the heart of our society; thus the government has assumed a role in supporting vulnerable families via programs and resources. In the past, many of the policies governing these programs excluded the very people they served from meaningful decision making in how the programs were administered. Service recipients were also excluded from decisions being made for their families and children. In the traditional system, parents were viewed as unnecessary in, or as impediments to, the interventions designed for children. They were given a one-size-fits all intervention and expected to make it work. Alternatively, they were seen as “helpers” in carrying out professionally prescribed plans. As Fondacoro and Weinberg (2002) stated:

The disadvantaged, and particularly their children, were seen as unconsenting participants in providing programs that perpetuated rather than eliminated victim blaming. The prevention programs were criticized for their deficit orientation and their attempt to train the disenfranchised to remediate their personal deficits and to adapt to the status quo. (p. 481)

The parent movement has sought to remedy these failings and become full partners in the care of children. The first of these movements, and do date the most successful, was the parent movement around children with developmental disabilities. It was started by predominantly White, middle-class women. The family movement in children's mental health never gained the same momentum or garnered the same support of the public. It would be easy to suggest that these differences exist because the parents who have started the parent movement for parents raising children with mental illness children are: (a) low-income; (b) often people of color; and (c) and dealing with the stigma associated with those two labels as well as with the stigma of raising a child with mental illness.

Although the federal government initially funded family-run organizations, it has ceased to do so under SOC grants. With no research to back the efficacy of this approach and the large number of organizations that were dismantled after losing their grant funding, the government gave up. It had no responsibility to the families because it controlled all of the power and resources. Other factors that led to the demise of family-run organizations were the bureaucratic structures and the systems by which they operated. By their very nature, these type of systems are resistant to change, particularly from outside forces. The providers within these systems all had an impact on the family-run organizations: many were helpful but many more were not. Their helpfulness was

probably reduced by the lack of training and/or support they had in fostering empowerment. Furthermore, many of the providers did not, themselves, feel empowered.

Last, although the federal SOC grants mandated that grant sites develop family-run organizations and obtain federal nonprofit status for them, little information was provided to help parents learn how to manage the operations of such organizations. Staffing, personnel, funding, budgets, audits, taxes, and reports were new to most of these parents. Their learning curve was steep because they needed to become familiar with the structures and functions of multiple service systems as well as learn to advocate, run support groups, and provide training. Some of these roles were mandated, as part of the funding structure of the family-run organizations, but many parents discovered that this work was their passion.

Most parents were not interested in running an organization; they wanted to serve other families. Despite this difference in motivation, and the barriers described in the previous paragraphs, parents succeeded in so many ways. They transformed themselves, and in many cases they transformed the practitioners with whom they worked closely to provide services for their own and other people's children. Although most of the family-run organizations in this study are gone, their demise was not a failure on the part of the mothers who started them and ran them. The data from this study show that parents who experienced the phenomenon of staffing parent-run organizations became transformed. They have been irrevocably changed. They found their voice, their ability to act, and their power. They are a success story.

The results of this study confirm that parents who experienced the phenomenon of staffing family-run organizations feel empowered. They have a newly defined sense of identity that countermands durable negative stereotypes; they are able to build robust social support systems; and they use their voice to act upon their wants and needs. Through experiencing this phenomenon, they have changed for the better. The systems that serve them, however, have not. One of the fundamental flaws in SOC grants was that the entire burden for creating long-term systemic change was placed upon these parents: the people outside the system who were most in need of effective services, and who were also facing significant challenges as women raising children with mental health challenges.

The success of the SOC grants relied upon transformation of individuals and particularly upon the empowerment of mothers; yet, the grants ignored the larger social-political systems that engendered this disempowerment. Parents were invited to the table as participants, but this table had been created by the same patriarchal system that perpetuates the dominant cultural narrative. Professionals were instructed to make room at this table for the family voice, but were never given the option of creating an entirely new table, one that was built with the voices of all stakeholders. The SOC grants emphasized changing the power structure of the systems, but providers retained control as well as the power to choose if, when, and how often to include family voice (McDonald & Keys, 2008). Until that choice no longer rests entirely in the hands of the people who already hold the power, true empowerment for families within the SOC and all publicly funded health and human service delivery systems remains elusive.

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## **APPENDIX A**

### **INTERVIEW PROTOCOL**

Below are a series of questions that will guide the interview process. The questions can be asked in any order, or may be used as a prompt to encourage the participant to elaborate further on an answer.

#### **Before Involvement with Staffing a Family Organization Under SOC:**

What was your life like prior to SOC involvement?

Prior to SOC, how competent did you feel in accessing services?

Were you able to access all of the services you needed for your child? If so, how?

If not, what challenges did you face?

Did you feel in control of your life, your child's service needs? Please explain.

#### **During Involvement with Staffing a Family Organization Under SOC:**

How and why did you get involved with the family organization?

Can you describe some of the things you did while working for the family organization?

How much control did you have over events and resources related to your role in the family-run organization? Do you think there was a relationship between control of the resources and the fact that you are a woman (or man (if applicable))?

How much control did you feel you had in influencing human service systems in your county in general; and specifically, how much control did you feel in influencing the services received by your child? What factors do you think

helped or hindered the amount of influence you had over the Standard of Care system and for your family?

Do you think your race, gender, and/or class had anything to do with your experiences with SOC? With your level of influence? If so, please explain.

Did you have relationships with other people who you could count on, and they could count on you, in regards to your child's mental health needs? Please describe the characteristics of these people (gender, role in your life, etc.)

After Involvement with Staffing a Family Organization Under SOC:

What has changed about your life since the grant funding has ended?

Are you still involved in SOC activities or any other system reform activities?

Is the family-run organization still in existence? Please describe.

Overall, how do you feel about your role in staffing the family-run organization and the work you did there? Has it positively or negatively influenced your life?

In what ways was it positive or negative?

Do you still feel the same level of competence you described earlier – better or worse?

Is there anything you would have changed or done differently while being involved with the grant-funded SOC? If so, please explain.

Is there anything else would you like to share regarding your SOC experience?